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Non-Cardiac Chest Pain: the Role of Physical, Psychosocial, and Service-Related Factors in the Persistence of Pain and Health Service Use

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Candidate Thesis Declaration

I declare that this thesis, which I submit to RCSI for examination in consideration of the award of a higher degree of Doctor of Philosophy is my own personal effort. Where any of the content presented here is the result of input or data from a related collaborative research programme this is duly acknowledged in the text such that it is possible to ascertain how much of the work is my own. I have not already obtained a degree in RCSI or elsewhere on the basis of this work. Furthermore, I took reasonable care to ensure that the work is original, and, to the best of my knowledge, does not breach copyright law, and has not been taken from other sources except where such work has been cited and acknowledged within the text.

Signed Aisling Sheehan

RCSI Student Number 07210931

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Abstract

Chest pain is one of the most frequent complaints in medical settings, yet more than half of cases have no detectable cause. Once a cardiac cause has been excluded, patients are typically discharged with a label of non-cardiac chest pain (NCCP). Patients with NCCP have been shown to have poor outcomes in terms of continued symptoms, distress, and continuing concern about heart disease. In addition, NCCP represents a significant burden to health services. The aetiology and management of NCCP is under-researched and poorly understood. This study sought to examine the predictors of persistent pain and health service use for patients in whom a cardiac diagnosis had been excluded. It also sought to explore how patients interpreted their symptoms in the context of normal test results, and the impact of their experiences with health services on these interpretations.

A mixed-methods design was adopted. A prospective cohort study was initially conducted with 145 participants with chest pain who attended exercise stress testing and had normal test results. At one-year follow-up, 69% reported continued pain. In addition, nearly half of participants had returned to their general practitioner and one in ten had attended the emergency department for the investigation of chest pain. In logistic regression analyses, the variables heartburn, pain precipitated by movement, cardiac anxiety, illness perceptions, and lack of communication about test results were predictive of persistent chest pain. When participants with continued chest pain were categorised into persistent healthcare users and non-persistent healthcare users, these variables were predominantly associated with participants with persistent health service use for chest pain. In addition, a number of psychological variables including anxiety and depression distinguished the persistent service users. Employment appeared to be a protective factor against persistent pain and related service use.

A small sample of participants from this cohort was interviewed in a qualitative study informed by the principles of Interpretative Phenomenological Analysis (IPA).

Analysis revealed three predominant themes: 1) the disempowerment of normal test results; 2) limbo - the inner struggle of negating and relating to potential causes; and 3) the inadequacy of healthcare to validate and care for symptoms. The dynamic, complex process of interpreting symptoms and deciding whether to seek healthcare was illuminated.

The results indicate that interventions targeting the assessment of a potential gastro-oesophageal or musculoskeletal cause and the reduction of cardiac anxiety are likely to improve outcomes in these patients. Improved communication with patients is also indicated. Psychological factors appear to drive persistent service use and interventions targeting these are likely to reduce medical costs. Patients with NCCP are not a homogenous patient group and an individualised, stepped-care approach to management appears to be warranted.

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Presentations arising from the present study

Oral Presentations

'Psychological and service-related factors as one-year predictors of persistent non-cardiac chest pain'.

- Psychological Society of Ireland (PSI) Annual Conference. Galway, November 2011.
- European Health Psychology Society Annual Conference. Hersonissos, September 2011.
- Psychology, Health & Medicine Conference, PSI Division of Health Psychology. Galway, April 2011.

'Non-Specific Chest Pain: The Value of a Cognitive-Behavioural Model'. PSI Annual Conference. Wexford, November 2009.

Poster Presentations

'Psychological and service-related factors as one-year predictors of persistent non-cardiac chest discomfort.'. Research Day, Royal College of Surgeons in Ireland (RCSI). Dublin, April 2011.

'The role of psychological and iatrogenic factors in predicting reassurance in patients with normal cardiac test results: Short-term findings from a longitudinal observational study'.

- European Conference on Psychosomatic Research (ECPR). Innsbruck, August 2010.
- Research Day, RCSI. Dublin, April 2010.
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Abbreviations

ACS	Acute Coronary Syndrome
AMI	Acute Myocardial Infarction
B-IPQ	Brief Illness Perception Questionnaire
BPI-SF	Brief Pain Inventory – Short Form
CAD	Coronary Artery Disease
CAQ	Cardiac Anxiety Questionnaire
CBT	Cognitive-Behavioural Therapy
CHAIR	Coronary Heart Attack Ireland Register
CI	Confidence Interval
CPQ	Chest Pain Questionnaire
DSM	Diagnostic and Statistical Manual of Mental Disorders
ED	Emergency Department
FH	Familial Hypercholesterolemia
GERD	Gastro-Oesophageal Reflux Disease
GP	General Practitioner
GRQ	Gastro-Oesophageal Reflux Questionnaire
HADS	Hospital Anxiety and Depression Scale
HADS-A	HADS Anxiety Scale
HADS-D	HADS Depression Scale
HFA	Heart-Focused Anxiety
IHD	Ischaemic Heart Disease
IPQ-R	Illness Perception Questionnaire - Revised
IQR	Inter-Quartile Range
IPA	Interpretative Phenomenological Analysis
M	Mean
Md	Median
MI	Multiple Imputation
MVA	Missing Value Analysis
NCCP	Non-Cardiac Chest Pain
OPD	Outpatient Department
OR	Odds Ratio

PHQ	Patient Health Questionnaire
RACPC	Rapid Access Chest Pain Clinic
RCT	Randomised Controlled Trial
RR	Relative Risk
SD	Standard Deviation
SMR	Standardised Mortality Rate
SSRI	Selective Serotonin Reuptake Inhibitor

Chapter 1: Introduction

1.1 Introduction

This chapter provides an introduction to non-cardiac chest pain (NCCP) and an overview of the outcomes of patients with this symptom. The outcomes that will be considered include mortality, persistent chest pain, and persistent health service use. A discussion on the complexity involved in diagnosing and treating NCCP will also be presented. Common physical and psychological causes attributed to NCCP will be explored.

1.2 What is Non-Cardiac Chest Pain (NCCP)?

Chest pain is one of the most common presenting complaints in hospital emergency departments and other medical settings (Laederach-Hofmann & Messerli-Buergy, 2007; McMahon, Yates, & Hollis, 2008; Niska, Bhuiya, & Xu, 2010). It accounts for about 700,000 emergency department attendances in England and Wales each year (Goodacre et al., 2005) and almost 6 million in the United States (Niska et al., 2010). This accounts for six per cent of all adult attendees. Although chest pain is considered a hallmark symptom of coronary artery disease (CAD), it can have multiple causes which are frequently undetermined (Vodopiutz et al., 2002; Warner, 1995).

Once a cardiac cause has been eliminated, patients are commonly discharged from care with a label of 'non-cardiac chest pain' (NCCP). This is a diagnosis of exclusion which refers to "pain that is not attributable to coronary sclerotic etiology" (Laederach-Hofmann & Messerli-Buergy, 2007, p.189). Alternative labels referred to in the literature include 'atypical', 'functional', 'heart neurosis', 'non-coronary', 'syndrome X', 'unexplained', and 'unspecified'. The plethora of terminology for this condition demonstrates the complexity and lack of understanding of NCCP.

1.3 Epidemiology of NCCP

Population-based studies have demonstrated that chest pain is a common condition with a prevalence rate of approximately 25% (Bass, 2007; Fass & Achem, 2011). In a community survey with a sample of 13,538, chest pain was reported by one quarter of participants and was the fourth most common physical symptom reported after joint pains, back pain, and headaches (Kroenke & Price, 1993). Good quality epidemiological information is lacking however, which necessitates caution in interpreting these figures (Robertson, 2006). Nevertheless, chest pain seems to be a relatively common symptom and it appears that the minority choose to seek medical attention. Gerstenkorn (1990) examined possible angina pectoris in a community sample of 4,734 individuals, and interviews revealed that 38% indicating probable angina pectoris had not sought medical help.

Although there are no systematic reviews on the prevalence of NCCP in individuals who seek healthcare for chest pain, observational studies have demonstrated that approximately half have no detectable organic cause for their symptoms and are therefore deemed to have NCCP (Ågård, Bentley, & Herlitz, 2005; Bass, 2007; Knockaert, Buntinx, Stoens, Bruyninckx, & Delooz, 2002; Mayou, Bryant, Forfar, & Clark, 1994; Pope et al., 2000; Robertson, Javed, Samanl, & Khunti, 2008; Sheps, Creed, & Clouse, 2004; Spalding, Reay, & Kelly, 2003). In Ireland, the Coronary Heart Attack Ireland Register (CHAIR) collects information on hospital patients admitted with suspected or confirmed acute coronary syndromes in eight acute hospitals in Ireland. From July 2002 to the end of June 2006, out of 13,227 admissions, 57% (7483) were discharged without a diagnosis of acute coronary syndrome, 77% (5573) of whom were discharged as NCCP (Health Service Executive, 2007). These rates do not include patients presenting to emergency departments with chest pain who have not been admitted, and the prevalence of NCCP is therefore likely to be higher. No Irish data has been collected specifically on NCCP prior to this study.

The rate of NCCP appears to be higher in primary care settings. In a study aimed at determining the prevalence of ischaemic heart disease (IHD), out of 577 patients

with newly onset chest pain recruited from three primary health centres in Sweden, only 8% were diagnosed with IHD following a bicycle exercise test, a further 9% required further investigation, and in 83% of participants IHD was excluded (Glombiewski et al., 2010). The proportion of NCCP appears to be lower in studies carried out in chest pain clinics. For example, research conducted in a newly established rapid access chest pain clinic (RACPC) in England found that 52% of 456 patients were discharged with NCCP (Dumville, MacPherson, Griffith, Miles, & Lewin, 2007). Another study in a chest pain clinic found a similar rate of 49% of NCCP patients out of a total of 278 patients (Davie et al., 1998).

Estimating the prevalence of NCCP is challenging due to differing definitions, inclusion criteria, sampling methods, and the potential for undetected disease, including cardiac disease. Many studies exclude cardiac disease on the basis of a normal exercise electrocardiogram, yet in a meta-analysis of its diagnostic accuracy, a mean sensitivity of 68% and mean specificity of 77% was found (Gianrossi et al., 1989). This diagnostic accuracy has been shown to be lower in women (Kwok, Kim, Grady, Segal, & Redberg, 1999). Conversely, there are also many patients who have abnormal findings in non-invasive investigations (e.g., ST-segment depression in electrocardiograms), but have normal or non-significantly obstructed coronary arteries. Studies have reported rates of approximately 30% with normal arteries, of those undergoing costly angiography (Laederach-Hofmann & Messerli-Buergy, 2007; Spalding et al., 2003).

Some studies perform an extensive range of diagnostic tests, for example, a study by Knockaert and colleagues (2002) performed tests including echocardiography, gastroscopy and lung-scintigraphy, in order to exclude cardiac, gastro-oesophageal, and respiratory diseases. Most studies include patients with well-established medical conditions in their NCCP population, however, such as upper respiratory tract infections (Glombiewski et al., 2010). A further complication is that many patients with documented CAD can have pain that is not ischaemic in origin (Sheps et al., 2004), and some studies include patients with pre-existing CAD (e.g. Prina et al., 2004).

1.4 Diagnostic and treatment dilemma

The diagnosis and treatment of chest pain is a complex dilemma for medical professionals (Chahal & Rao, 2005; Schwartz, Trask, & Ketterer, 1999). During chest pain episodes, nearly all resources are understandably directed towards the exclusion of cardiac disease. Yet the majority of patients do not appear to have significant coronary artery disease. Once a cardiac cause has been excluded with reasonable certainty, a vast number of possible aetiologies (causes) spanning many disciplines need to be considered, while taking care not to over-use medical resources (Ågård et al., 2005). Examples of potential causes of NCCP are displayed in Table 1.1. This is by no means an exhaustive list, but serves to exemplify the complexity of the differential diagnosis of chest pain. Gastro-oesophageal and musculoskeletal causes are most predominantly associated with chest pain, while some claim that chest pain could be related to an undetermined cardiac cause.

1.4.1 Cardiac Syndrome X

The term 'Cardiac Syndrome X' was first termed by Arbogast and Bourassa (1973) to describe patients with normal coronary angiograms but chest pain suggestive of angina pectoris. Some postulated that the condition has an undetermined cardiac cause. Numerous theories have been proposed including an impairment in coronary flow reserve (Chauhan, Mullins, Petch, & Schofield, 1994), microvascular spasm (Hackett et al., 1987), undetectable abnormalities of small coronary arteries (Mosseri et al., 1991), oestrogen deficiency (Ross et al., 1996), patchy constriction of prearteriolar vessels (Maseri, Crea, Kaski, & Crake, 1991), and impaired endothelial function (Egashira et al., 1993). Recently, speculation has focused on neurophysiological differences in pain perception (Rosen, 2004). Many theories are speculative and an explanation remains elusive (Asbury & Collins, 2005; Schwartz & Bourassa, 2001).

Table 1.1 Examples of potential causes of non-cardiac chest pain (NCCP)

Unexplained cardiac	Cardiac Syndrome X Microvascular angina
Gastrointestinal	Gastric (e.g. gastro-oesophageal reflux disease (GERD)) Biliary tree (e.g. gallstones) Pancreatic (e.g. acute pancreatitis) Intra-abdominal masses (benign and malignant)
Musculoskeletal	Tietze's syndrome Costochondritis Fibromyalgia Precordial catch syndrome Slipping rib syndrome
Psychological	Anxiety Depression Panic disorder Hyperventilation Somatisation disorder
Other causes	Respiratory disorders Aortic disorders Pericarditis and myocarditis Pulmonary hypertension Herpes zoster Drug-induced pain (e.g. cocaine) Sickle cell crisis

1.4.2 Gastro-oesophageal disorders

The role of the oesophagus in the aetiology of chest pain has been greatly investigated. The heart and the oesophagus share a common nerve supply and abnormalities therefore can share a similar clinical presentation (Fang & Bjorkman, 2001; Schwartz & Bourassa, 2001). Research on the prevalence of oesophageal abnormalities in NCCP patients is scarce, and a wide range of 22%-80% has been reported (Lenfant, 2010; Richter, Bradley, & Castell, 1989). For example, in a study of 204 non-AMI patients, 42% were diagnosed with gastro-oesophageal diseases (Fruergaard et al., 1996). Gastro-oesophageal diseases include gastro-oesophageal reflux disease (GERD) and oesophageal spasm (see Table 1.1). Examination of the National Clinical Outcomes Research Initiative (CORI) database in the United States of America found that out of 3,688 NCCP patients undergoing an upper endoscopy

for their chest pain, 44% had normal results, compared to 39% of patients with GERD-related symptoms only (Dickman, Mattek, Holub, Peters, & Fass, 2007). This suggests that a high proportion of NCCP could be GERD-related.

Gastroenterologists have argued that gastro-oesophageal disorders are the most frequent causes of NCCP (Fang & Bjorkman, 2001; Lenfant, 2010). Achem (2008, p.642) has stated that "by far, gastro-oesophageal reflux (GER) is the most common cause of NCCP and the better studied." It has therefore been suggested that it may be more appropriate for NCCP patients to be managed by a gastroenterologist, once a cardiological cause has been excluded (Shekhar & Wohorwell, 2008). Bennett (2001) cautions that there is an inevitable selection bias in the examination of oesophageal disorders and assertions of a gastro-oesophageal cause are therefore not objective. Nevertheless, he argues that the oesophagus is undoubtedly a source of chest pain and should be considered. The mechanisms for oesophageal pain are poorly understood, however (Fang & Bjorkman, 2001). In addition, treatment of oesophageal disorders does not necessarily correspond with improvement in oesophageal motility, despite symptomatic improvement (Achem 2008).

1.4.3 Musculoskeletal causes

Another highly investigated potential cause of NCCP is the musculoskeletal system. This includes skin, bones, muscles, tendons, soft tissue, and cartilage of the chest. The area where the heart lies, in the thoracic compartment, has an elaborate anatomy made up of all these elements and has a complex nerve supply (Schwartz & Bourassa, 2001). A chest wall syndrome is a musculoskeletal disorder of the anterior chest wall which is associated with chest wall tenderness (Verdon et al., 2007).

The proportion of NCCP patients with a chest wall syndrome has been estimated at 10% in cardiology settings (Schwartz & Bourassa, 2001). A slightly higher proportion of 15% with musculoskeletal pain has been found in an emergency room setting (Knockaert et al., 2002). Even higher proportions have been found in primary care.

In a primary care study of 672 cases of chest pain, 45% were given a diagnosis of chest wall syndrome, which was three times more frequent than cardiac pain in this sample (Verdon et al., 2007).

The diagnosis of chest wall syndrome can often be made at the bedside since the provocation of pain by simple manoeuvres is suggestive of a musculoskeletal cause (Schwartz & Bourassa, 2001). However, the presence of tender points in the chest is indicative of a number of other conditions including coronary heart disease and pleurisy (Verdon et al., 2007). NCCP therefore remains a complicated diagnostic challenge.

1.4.4 Psychological causes

The association of chest pain with emotional state was first recognised in soldiers following the First World War (Robertson, 2006). Soldiers frequently report symptoms of chest pain which is theorised to be caused by the trauma of combat (Alcaras & Roper, 2006). In some cultures, a connection between affective life and chest sensations is commonly recognised. In a study of medical discourse in Maragheh, Iran, from 1972 to 1974, it was discovered that people commonly experienced heart distress as a physiological sensation and believed it to be associated with feelings of sadness, anxiety, and a sense of being trapped (Good & Good, 1982). Their explanatory model of the heart was based in Galenic-Islamic medicine, where the heart was considered an organ of affect rather than a means of circulation of the blood.

Psychological factors attributed to non-cardiac chest pain include anxiety disorders, depression, neuroticism, hypochondriacal behaviour, hypervigilance of bodily cues, alexithymia, and somatisation. Incidence rates of a co-morbid psychiatric diagnosis range from 47-80%, with panic disorder ranging from 11-76% (Dammen, Arnesen, Ekeberg, & Friis, 2004; Eslick, 2008; Kuijpers, Denollet, Wellens, Crijns, & Honig, 2007; Maunder, 1998; Okpa et al., 2003; Potts & Bass, 1995; Robertson et al., 2008). For example, Dammen and colleagues (2004) detected psychiatric disorders among 73% of non-cardiac chest pain patients and panic disorder among 41%.

When compared to patients with cardiac chest pain, patients have similar (Dammen et al., 2004; Eken et al., 2010; Zachariae, Melchiorsen, Frøbert, Bjerring, & Bagger, 2001), or greater (Cormier, Katon, Russo, & Hollifield, 1988; Karlson, Wiklund, Bengtson, & Herlitz, 1994; Kisely, Creed, & Cotter, 1992; Laederach-Hofmann & Messerli-Buergy, 2007; Olson et al., 2003) levels of psychological morbidity. It is therefore not possible to distinguish cardiac from non-cardiac chest pain on the basis of psychological factors.

Panic is the most thoroughly researched disorder in relation to chest pain due to the prominence of chest pain in panic disorder and general anxiety disorder (Robertson, 2006). Panic disorder is the recurrence of unexpected panic attacks which are discrete periods of fear or discomfort accompanied by at least four cognitive or somatic symptoms such as palpitations, chest pain, trembling, nausea, or fear of dying (American Psychiatric Association, 2000). A review of the literature reported co-morbidity of panic disorder and non-cardiac chest pain ranging from 16% to 76% (Maunder, 1998). For example, in a study of 94 participants with angiographically normal coronary arteries, 34% met the criteria for current panic disorder according to a structured psychiatric protocol (Beitman et al., 1989). Katon (1984) reports that 89% of panic-disordered patients referred by primary care physicians for a psychiatric consult initially presented with somatic complaints, with chest pain symptoms being one of the most common. Studies comparing NCCP patients to independent samples of patients with panic disorder are lacking, however. One study with a small sample of 22 NCCP patients found that they had similar levels of panic symptoms to panic disorder patients attending psychotherapists, but panic disorder patients reported greater severity of symptoms (Beck, Berisford, Taegtmeyer, & Bennett, 1990).

Pathophysiological mechanisms such as hyperventilation in panic have also been implicated in the aetiology of non-cardiac chest pain. For some patients, chest pain can be provoked through simple breath-holding or hyperventilation provocation tests. Hyperventilation or emergency breathing causes panting, a rise in blood

pressure and heart rate, and increases adrenaline in the blood, which can cause strange sensations, palpitations and a chest pain like angina pectoris (Bass, 2007).

Somatisation is another psychological variable theorised to affect the experience and interpretation of both cardiac and non-cardiac chest discomfort and subsequently impact healthcare-seeking behaviour. It is defined as the degree of sensitisation to body activity and physiological functioning (Warner, 1995). Cheng and colleagues (2003) revealed that unexplained chest pain patients had a greater tendency to monitor danger cues in their bodily conditions and the environment compared with rheumatic and healthy participants. In addition, another study found a prevalence of 19% of somatoform pain disorder amongst NCCP patients (Dammen et al., 2004). Warner (1995) found that somatic awareness was the most important factor in a logistic regression model that modestly but significantly predicted presence or absence of CAD. There was also a weak but significant inverse correlation between level of somatic awareness and degree of CAD ($r=-0.293$, $p<0.05$). A reliance on verbal reports of remembered physiological sensations is a limitation to the study, however. Nevertheless, similar findings were reported by Frasure-Smith (1987), particularly in a group of men without a previous history of acute myocardial infarction. Panic and somatoform disorders have been shown to be three times more likely than cardiac disease in a sample of 198 patients attending a cardiac outpatient unit for the evaluation of chest pain or palpitations (Jonsbu et al., 2009). Further examination of these psychological variables in the context of NCCP is therefore warranted.

1.4.5 Complexity in diagnosis

The identification and management of NCCP "remains a complicated and under-researched area that demands increased attention" (Schwartz et al., 1999, p.335). The aetiology may overlap across disciplines, which further complicates its management. NCCP is increasingly believed to be caused by the interaction between physical and psychological factors (Bass, 2007; Schwartz et al., 1999). Disciplines tend to study NCCP in isolation, however, and understanding of the condition is therefore greatly limited. Gastroenterology, internal medicine,

orthopaedics, psychiatry, and psychology have all explored potential mechanisms of NCCP, but very little guidance has been provided to practitioners for the management of these patients.

1.5 Economic burden of NCCP

Despite many protocol-driven diagnostic assessments (e.g. Amsterdam et al., 2010; Kontos, Diercks, & Kirk, 2010; Than et al., 2011), and the introduction of rapid assessment chest pain services (Capewell & McMurray, 2000) which aim to minimise inappropriate admissions and testing, NCCP represents a significant economic burden to the health services. Overall, an estimated 2-5% of all admissions to the Emergency Department are for NCCP (Eslick, Jones, & Talley, 2003; Knockaert et al., 2002). Research has demonstrated that the use and cost of medical investigations for patients with medically unexplained symptoms is greater than other frequent attenders (Reid, Wessely, Crayford, & Hotopf, 2002). Evaluations on the cost of health service use by NCCP patients are lacking, yet the overall cost to the healthcare system has been estimated at 1.8 billion dollars per year in the United States (Achem & De Vault, 2000) and 30 million dollars in Australia (Eslick & Talley, 2000). In addition to the economic impact of NCCP, the personal impact of NCCP has been demonstrated to be significant in many cases. A large proportion of NCCP patients have poor outcomes, which will be explored in the following section.

1.6 Outcomes

In addition to the economic cost of NCCP, personal costs are evident. Symptoms, distress, related disability, and continuing concern about heart disease have been found to persist in patients to a high degree (Bass, 2007; Schwartz et al., 1999). The prognosis in terms of mortality continues to be debated.

1.6.1 Mortality

The natural history and prognosis of non-cardiac chest pain is not well established. Initial research appeared to indicate that patients with NCCP were at a higher risk of mortality than the general population, yet some more recent studies have demonstrated unremarkable cardiovascular outcomes for non-ischaemic chest pain cases (Schwartz et al., 1999; Spalding et al., 2003; Taylor et al., 2008). For example, in a large study of 8762 patients with benign chest pain, (Sekhri, Feder, Junghans, Hemingway, & Timmis, 2007), 2.7% died of coronary heart disease or had an episode of acute coronary syndrome (ACS) or unstable angina over the following 3 years, which was comparable to a matched population.

However, McMahon and colleagues (2008) propose that patients discharged with a non-specific diagnosis are at higher risk of mortality than the general population. In their prospective study of 786 patients presenting to an emergency department in the United Kingdom, relative risks of all-cause 5-year mortality for men and women under 65 years were 2.1 (95% confidence interval (CI) 1.4-2.8) and 2.6 (95% CI 1.4-3.8), respectively, compared with expected mortality in an age-matched and sex-matched local population.

While this study demonstrated a reduced 5-year survival for NCCP patients, an examination of Swedish registers demonstrated an improvement in outcomes for patients with NCCP in recent years. Data on 235,855 patients hospitalised with a first-time diagnosis of unexplained chest pain over a wide time span of 19 years were examined, and age-standardised mortality rates (SMRs) were shown to have decreased in more recent years to the rate found in the general population (Fagring et al., 2010). Although an elevated one-year mortality rate was found for men and women hospitalised between 1987 and 1996, this was not evident for the 77,782 patients admitted between 2002 and 2006. However, men aged between 75 and 84 were at a slightly elevated risk (SMR=1.14, 95% CI 1.01-1.28).

Reasons for the lack of consistency in morality findings are unclear. The varying definitions of NCCP and the differing inclusion and exclusion criteria employed by studies is problematic (Munk et al., 2008). For example, the inclusion of patients with pre-existing CAD could account for an increased risk of mortality. A study by Prina and colleagues (Prina et al., 2004), which prospectively evaluated adverse cardiac events in 230 patients with NCCP presenting to emergency departments, found that patients with pre-existing CAD had a higher odds of adverse cardiac events (OR=9.5, 95% CI 2.0-45.8). Studies need to also account for other potential risk factors, such as diabetes mellitus, which was shown to also increase the odds of adverse cardiac events in this study (OR=7.1, 95% CI 1.8-27.2).

An improvement in diagnostic methods could account for the possible improvement in mortality outcomes for NCCP patients. If a higher mortality risk does exist, it is possible that patients have undetected disease, or high levels of psychological co-morbidity found in this population group could partially explain the risk. A number of psychological variables have been associated with increased risk of fatal coronary artery disease including depression (Van der Kooy, van Hout, Marwijk, Marten, Stehouwer, & Beekman, 2007) and anxiety disorders (Roest, Martens, de Jonge, & Denollet, 2010).

1.6.2 Continued chest pain

A high proportion of NCCP patients continue to experience chest pain. Prospective follow-up studies demonstrate that approximately 40-75% of patients with NCCP continue to experience chest pain. As with all outcomes for NCCP, it is difficult to determine the prevalence of persistent chest pain due to the employment of differing definitions, recruitment settings, and measures. Varying response rates have also been achieved which necessitates cautious interpretation of figures. For example, Spalding and colleagues (2003) found that symptoms were persistent in 61% of 61 participants recruited from coronary care and medical assessment units at one-year follow-up, yet this number of participants represented just 58% of the original sample.

A slightly higher response rate of 69% was achieved in a retrospective cohort study of 235 patients without cardiac chest pain who attended a Rapid Access Chest Pain Clinic (RACPC) (Dumville et al., 2007). At 8 month follow-up, 47% of 161 respondents reported they had ongoing chest pain, 9% experienced chest pain every day, and 34% described it as a moderate or severe problem in their lives. A similar rate of persistent chest pain was found in a prospective cohort study of 74 primary care offices in Germany. Out of 807 patients presenting with nonspecific chest pain, 55.5% reported persistent chest pain at 6-month follow-up (Glombiewski et al., 2010)

The highest reported rate of persistent pain is 90%, which was found in a prospective study of 126 NCCP patients referred to the emergency room at two-year follow-up (Eslick & Talley, 2008b). The fairly low response rate of 65% may account for this higher rate. Although it is reported that participants and non-participants did not differ on a range of demographic and clinical variables, responses to chest pain measures are not reported on. At the other extreme, a study by Davie and colleagues (Davie et al., 1998) found that only 14% reported persistent chest pain at six-month follow-up. This study recruited 126 NCCP patients referred to a chest pain clinic by general practitioners. Although quite a high follow-up rate of 88% was achieved, it is unclear how pain at follow-up was measured and who performed the follow-up assessment. It appears to be an anomaly within the literature on NCCP, and the surprising nature of these findings has been commented on (Kinane, 2000).

1.6.3 Health service use

Due to persistent or recurrent chest pain, many patients have been found to continue to use medical services for the investigation of chest pain. Continued help-seeking can necessitate expensive investigations and potentially inappropriate use of medication. Studies have demonstrated that approximately 14-52% of NCCP patients are persistent in seeking healthcare for chest pain. Varying rates of continued health service use have been detected in NCCP patients, most likely for reasons identified previously such as varying definitions, recruitment settings,

measures, and inclusion criteria. In addition, studies do not tend to control for chest pain, which is necessary since health service use is unlikely to continue in the absence of continued symptoms.

In a large study of 807 NCCP patients recruited from primary care, 52% had visited a medical specialist at least once at 6-month follow-up (Glombiewski et al., 2010). A prospective study which recruited patients from an emergency department yielded similar results (Spalding et al., 2003). Out of 108 NCCP participants, 51% had undergone further investigation for their chest pain at one-year follow-up and 14% had been admitted to hospital with similar or related symptoms. In an 8-month follow-up of 161 NCCP patients who had attended a chest pain clinic, 28% had visited their GPs at least once.

When the examination of health service use is restricted to hospital care the rate of persistent health service use appears to be lower. For example, in a study of 230 patients discharged from the emergency room with a diagnosis of chest pain of undetermined origin, 14% returned to the emergency department within 12 months of discharge (Prina et al., 2004). No other health service settings were reported on in this prospective study. In a study with a longer follow-up period of ten years, 49% of 320 NCCP patients were found to re-attend the emergency department, 42% attended cardiology clinics, and 15% attended gastroenterology clinics (Leise et al., 2010).

There has been very little examination of mental health service use in patients with NCCP. While Eslick and Talley (2004b) found that 8% had attended an alternative therapist and 10% had attended a psychologist for their chest pain in the previous year prior to attending an emergency department, in the study of 807 NCCP patients in Germany by Globmiewski and colleagues (2010), only 6 out of 807 participants with NCCP in primary care had been referred to mental health specialists at 6-month follow-up. This is despite free psychological consultations in the healthcare system in Germany, and the high rates of psychological morbidity found in this patient group (see section 2.6).

1.6.4 Reassurance and uncertainty

It is important that patients with NCCP are not given a diagnostic label of coronary disease and are reassured about the normality of their heart (Schwartz & Bourassa, 2001). Medical reassurance is achieved if patients' worries are alleviated and a change in behaviour, understanding, or thoughts occurs (Linton, McCracken, & Vlaeyen, 2008). Yet patients often receive insufficient or inconsistent information and are typically offered no additional treatment beyond feedback that there is nothing physically wrong (Chambers & Bass, 1998). Patients may also be given a probable diagnosis of angina prior to diagnostic testing. The term angina can be used to refer to the symptom of chest pain, which may or may not be due to ischaemia (e.g. Quyyumi, Wright, Mockus, & Fox, 1985), yet patients may assume it is a cardiac diagnosis. Although it is assumed that informing patients that their test results are normal is sufficient in reassuring them, this is not empirically supported.

Studies of chest pain patients find that many are not reassured by their test results (Channer, James, Papouchado, & Russel Rees, 1987; Goodacre, Mason, Arnold, & Angelini, 2001). Dumville and colleagues (2007), in their study of 161 participants attending a Rapid Access Chest Pain Clinic, found that 50% were not convinced by normal cardiac test results and maintained the belief of having a heart condition. In this study, 81% of participants also reported that they had not been given any explanation for their pain. Ordinal logistic regression revealed that patients were less likely to believe that their pain was cardiac if they no longer had pain (OR=0.31, 95% CI 0.12-0.73, p=0.007) or had experienced pain prior to their appointment for a longer period of time (OR=0.97, 95% CI 0.94-1.00, p=0.025). In an older study of 24 NCCP patients (Lantinga et al., 1988), 25% believed they had heart disease one year after normal cardiac catheterisation, 42% were unsure, and only one third believed they did not. Spalding and colleagues (Spalding et al., 2003) asked patients discharged with a non-cardiac diagnosis about their perceived cause of chest pain, and only 30% correctly identified their diagnostic category when questionnaire responses were compared to their medical records.

The lack of a perceived cause for symptoms can be worrying. A qualitative study conducted by Jerlock and colleagues (2005) found that NCCP patients worried about a missed diagnosis, or feared that their symptoms would persist. The lack of diagnosis results in a lack of perceived power to alleviate symptoms and lack of knowledge of the urgency of symptoms (Good, 1994, as cited in Jerlock et al., 2005). Semi-structured interviewing with 38 chest pain patients discharged without a diagnosis revealed that over two thirds of patients had unanswered questions and concerns (Ågård et al., 2005). One female aged 44 years reported: "It is like someone telling you that you don't have that much pain ... So now I have to go home without any idea of what it might have been. It is not normal to get pain like that it has to be something. You don't go to the emergency department just for fun" (Ågård et al., 2005, p.341). The lack of reassurance about the exclusion of heart disease is theorised to contribute to continued pain, disability, and health service use (Bass, 2007; Schwartz et al., 1999).

The question of why patients are not reassured remains unanswered. Blame has been placed on both contextual and patient factors. Some have labelled lack of reassurance as abnormal illness behaviour or neuroticism or even an inherent personality trait (Donovan & Blake, 2000; McDonald, Daly, Jelinek, Panetta, & Gutman, 1996; Ring, Dowrick, Humphris, Davies, & Salmon, 2005). However, most acknowledge that reassurance is a much more complex process. Other theorists have focused on service-related factors including the prescription of antianginal medications before diagnostic testing, use of a probable diagnostic cardiac label, lack of explanation for distressing and continuing symptoms, lack of communication leading to contradictory and conflicting advice, or inconsistent and ambiguous information (Bass & Mayou, 2002).

1.6.5 Psychosocial outcomes

The psychosocial outcomes of NCCP patients have been shown to be poor. In a recent systematic review of 12 studies examining psychological outcomes in NCCP patients recruited from emergency care (Webster, Norman, Goodacre, & Thompson, 2011), participants were found to have worse quality of life than

healthy controls. Work absenteeism due to chest pain has been estimated at 29%, and 63% have reported significant interruptions to daily activities including work, housework, and visiting friends (Eslick & Talley, 2004b). Approximately 50% have been reported to regard their lives as significantly disabled (Bass, 2007). Patients have described how their chest pain can invade all everyday activities (Jerlock et al., 2005). Endurances reported include fear, anxiety, uncertainty, stress, loss of strength, resignation, and despair (Jerlock et al., 2005).

High levels of stress have also been reported in this population group (Fagring et al., 2008). In a study of 179 NCCP patients recruited from the emergency department, 18% reported permanent stress at work and 7% reported permanent stress at home during the last year (Jerlock, Gaston-Johansson, Kjellgren, & Welin, 2006). Another study of 2341 patients with unexplained chest pain found that levels of stress, sleep problems, and health-related quality of life were worse than in a population-based reference group of 1069 individuals (Jerlock et al., 2008).

Due to the implied threat of heart disease, it is not surprising that many patients undergo considerable emotional distress (Schwartz et al., 1999). The arousal of anxiety in patients with a suspicion of heart disease is understandable, and referral for a test lends credence to this anxiety (McDonald et al., 1996). High levels of psychological morbidity have been found in this patient group (see section 1.4.4). It is unclear whether psychosocial variables are causal or maintaining factors for chest pain and related health service use, or whether they are simply a consequence of the distressing nature of the physical symptom of chest pain and a lack of explanation for it.

1.7 Gap in the literature

NCCP patients evidently represent a large proportion of patients seeking medical care for chest pain, yet they appear to have poor outcomes. Due to the heterogeneity of studies, including varying definitions, settings, and assessment methods, these outcomes are poorly understood. In addition, very little research

has examined the reasons for poor outcomes, and in particular, what factors drive persistent pain and health service use. Increased understanding would facilitate the development of the effective treatment and management of NCCP patients. This study aimed to examine the predictors of persistent pain and health service use in NCCP patients. Patients with a prior history of CAD were excluded from participation due to potential confounding, and participants were recruited from both emergency and primary care settings in order to examine a more representative sample of NCCP patients.

1.8 Summary

Non-cardiac chest pain (NCCP) accounts for approximately half of chest pain cases in medical settings. The most common causes examined in NCCP are gastro-oesophageal, musculoskeletal, and psychological. Determining the aetiology is difficult due to varying definitions, inclusion criteria, and sampling methods employed by studies. The prognosis of patients is poor in terms of persistent symptoms, health service use, reassurance, distress, and disability. Due to the lack of understanding of the aetiology of NCCP, it represents a complex diagnostic and treatment dilemma for practitioners. The following chapter explores the reasons for poor outcomes. In particular, it examines the potential predictors of persistent NCCP and related service use.

Chapter 2: Persistence of NCCP and Related Service Use

2.1 Introduction

This chapter presents an overview of theories and research on the persistence of NCCP and related health service use. In particular, it considers a biopsychosocial model developed by Bass and Mayou (2002), which attempts to account for the complexity of the phenomenon. The evidence in support of the elements of this model is evaluated.

2.2 Cause of poor outcomes

The reasons behind the negative outcomes for non-cardiac chest pain (NCCP) patients, discussed in the previous chapter, have been largely unexplored. A comprehensive understanding of its origins eludes both research and clinical communities (Robertson, 2006). Diverse medical specialities have investigated the phenomenon, each within their own discipline-specific interpretation of symptoms, which complicates conceptualisation (Mayou, 1989). Despite this, the aetiology is increasingly believed to be multifactorial due to interacting physical and psychological factors (Bass, 2007; Schwartz et al., 1999). It is argued that "one cannot do justice to the complex nature of reality by merely distinguishing between underlying somatic and psychological causes" (Laederach-Hofmann & Messerli-Buergy, 2007, p.188).

2.3 Biopsychosocial approach

Fava and Sonino (2008) argue that the traditional biomedical approach, i.e. the focus on physical processes, and the focus of medical specialities on organ systems, is inept. Many argue that a more holistic approach to medicine is needed, that not only considers the cellular and organic levels, but also the interpersonal and environmental levels (Engel, 1977; Fava & Sonino, 2008; Lupton, 2003). This is

particularly the case for medically unexplained symptoms. An alternative model, termed the 'biopsychosocial model' by Engel (Engel, 1977), proposes that biological, psychological, and social factors must all be taken into consideration in healthcare. Indeed, all these factors have been implicated in the aetiology of NCCP. It is argued that a biopsychosocial approach embodies the aim of medicine proposed by the ancient Greek physician Hippocrates: cure sometimes, treat often, and comfort always (Ghaemi, 2009).

Bass and Mayou (2002) propose that a biopsychosocial approach to NCCP should be adopted and have developed a model of explanation incorporating biological, psychological, and social factors. This model is displayed in Figure 2.1. They maintain that NCCP is best understood as an interaction between normal or abnormal physiological processes (such as palpitations, oesophageal spasm or reflux), psychological factors (such as how somatic sensations are perceived, interpreted, and acted on), and the behaviour and reactions of other people, including doctors. Factors which may predispose people to misinterpretation of symptoms having a cardiac cause (e.g. previous disease or illness experience), and factors which may maintain symptoms (e.g. iatrogenic factors) have also been defined. Bass and Mayou (2002) argue that it is the interaction of physical sensations with psychological and social factors that causes chest pain. They propose that whatever the cause of the chest pain, it is the interpretation of the cause that determines outcomes for patients. There remains a need to establish the validity of the model, although research has examined components of the model, which will now be discussed.

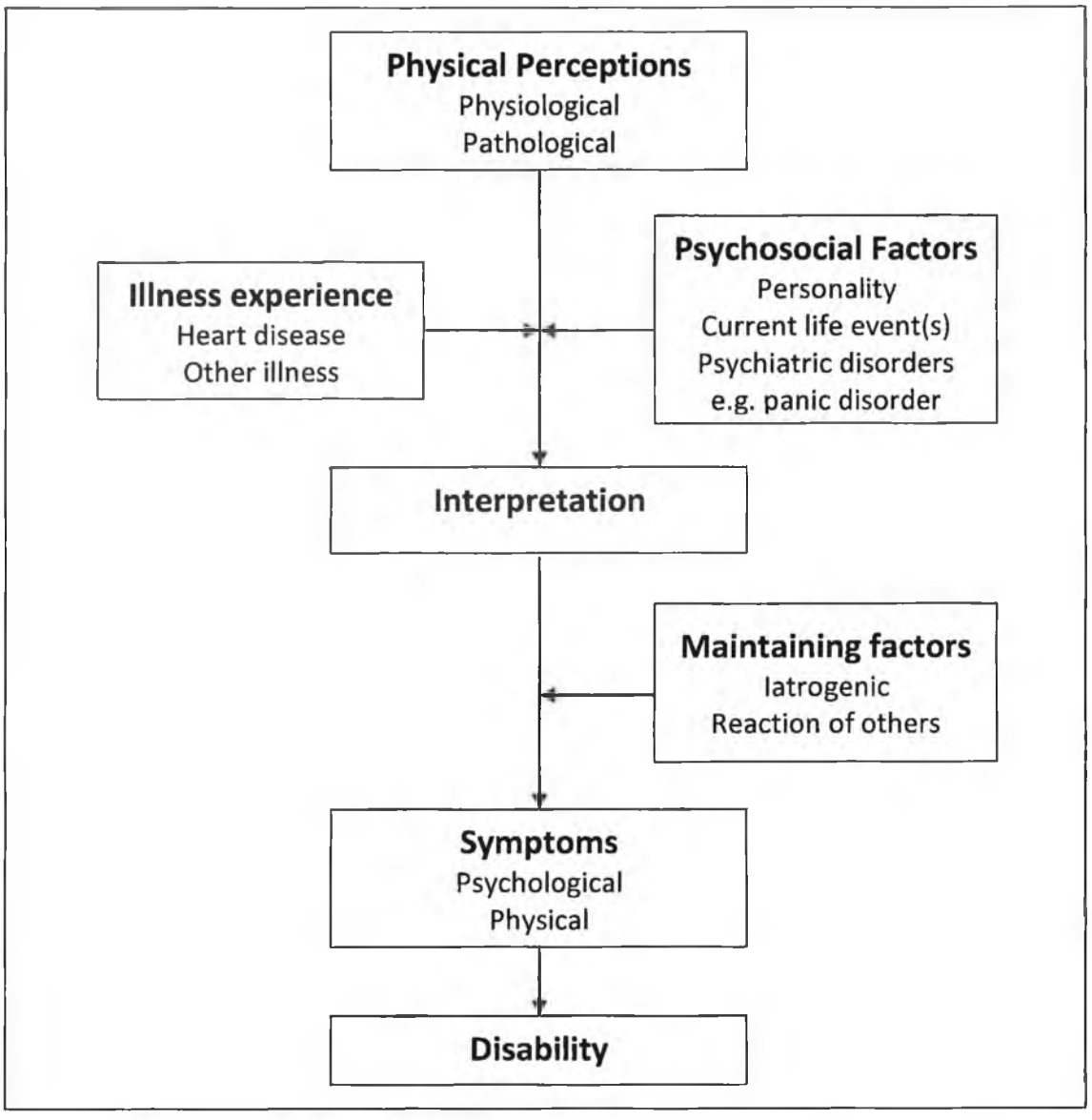


Figure 2.1 Model of NCCP by Bass and Mayou (2002)

2.4 Physical perceptions

The primary physical factors attributed to NCCP are a variety of common gastroenterological conditions and musculoskeletal disorders, as already discussed in section 1.4. Normal physiological processes such as extrasystoles or hyperventilation can also account for chest pain. No studies have examined the relationship between physical factors and persistent chest pain in NCCP, but one study did examine its association with health service use. In a cross-sectional study of patients attending an emergency department with chest pain (Eslick & Talley,

2004b), participants who experienced acid regurgitation at a frequency of at least once per month were more likely to have consulted medical practitioners in the previous 12 months for their pain (OR=2.54, 95% C 1.24–5.22, p=0.01), even when other physical factors and psychological factors were controlled for. However, chest pain variables, which were reported to be related to health service use, were not controlled for in the multivariate analysis. In particular, chest pain onset was not included and this needs to be adjusted for due to the cross-sectional design. Participants who have been experiencing chest pain for a longer time period would be more likely to have previously sought healthcare. The other gastrointestinal factors examined were heartburn and dysphagia, but these were not related to prior health service use. Although the study has limitations, it appears that gastro-oesophageal causes could be related to poorer outcomes for NCCP patients. Further studies examining physical factors in NCCP are needed.

2.5 Psychological factors

Due to the high prevalence of psychological morbidity in NCCP patients, it has been implicated in the aetiology of NCCP. Studies of psychological morbidity have observed that approximately half or more have psychological disorders (see section 1.4.4). Most studies are cross-sectional and do not prospectively examine the relationship between psychological factors and patient outcomes, yet a small number of studies have examined this relationship. Nine studies examining the relationship between psychiatric morbidity and chest pain, and four studies examining its relationship with health service use were identified. The studies are detailed in Table 2.1 according to chronological order. A number of limitations to these studies were observed.

2.5.1 Psychological factors and persistent chest pain

One prospective cohort study of NCCP did not find a relationship between psychological morbidity and persistent chest pain (Kisely et al., 1992), but there were only 17 NCCP participants in this study and no statistics were provided to authenticate this claim. All other studies showed a relationship between

psychological morbidity and persistent chest pain (Bass, Wade, Hand, & Jackson, 1983; Potts & Bass, 1995; Tew et al., 1995; White et al., 2008). However, it is unclear how chest pain was measured in earlier studies, one study included participants with minimal CAD (Bass et al., 1983), and another did not disaggregate the data for NCCP and IHD patients (Tew et al., 1995). White and colleagues (White et al., 2008), found that 44% of participants had an Axis I psychiatric disorder according to the Diagnostic and Statistical Manual of Mental Disorders, Third Edition (DSM-III), which was cross-sectionally associated with more frequent chest pain (d=0.60). The longest follow-up of NCCP patients was eleven years (Potts & Bass, 1995), which found that participants with continued chest pain were more likely to have higher levels of a number of different psychological disorders including depression, psychoticism, somatisation and anxiety at follow-up. The relationship between baseline psychological scores and persistent chest pain was not examined, however.

Panic disorder and its relationship to persistent chest pain have been specifically examined by three prospective cohort studies of NCCP patients (Beitman et al., 1991; Dammen, Bringager, Arnesen, Ekeberg, & Friis, 2006; Fleet et al., 2003). Dammen and colleagues (2006) detected a high prevalence (73%) of panic disorder amongst 152 participants at baseline, and significantly more of these patients reported persistent chest pain at one-year follow-up (90% versus 72%). Analyses were not presented separately for patients with and without CAD, however, and consequently it is unclear whether this significant relationship would have applied specifically for NCCP participants. Fleet and colleagues (2003) found that 57% of participants with panic disorder at baseline had persistent chest pain at two year follow-up, compared to 31% without panic disorder (χ^2=17.3, p<0.05). This study had a large sample (n=301) and robust measures, yet the findings are only generalisable to NCCP patients presenting to emergency departments. Other NCCP patients such as those presenting to primary care need to be examined further, as well as the relationship between other psychological factors and persistent pain.

2.5.2 Psychological factors and persistent health service use

Research across a wide range of illnesses and symptoms has demonstrated an association between levels of anxiety and healthcare-seeking behaviour (Petrie & Pennebaker, 2004). A number of potential explanations for this association exist. It is argued that patients with higher levels of anxiety are more introspective and watchful for physical sensations. An alternative understanding is that symptoms of anxiety, such as tachycardia or dry mouth, can be misinterpreted as a sign of a physical illness (Petrie & Pennebaker, 2004). This can lead to inappropriate illness behaviour which reinforces somatic focus and mediates pain tolerance (Schwartz et al., 1999).

The relationship between psychological morbidity and healthcare use has not been well established in patients with NCCP, however. Fewer studies have examined predictors of persistent health service use, although studies have observed rates of continued service use without investigating their predictors (e.g. Dumville et al., 2007; Leise et al., 2010; Prina et al., 2004). Only four studies have been identified as examining the relationship between psychological factors and healthcare seeking behaviour (see Table 2.1). Three of these studies examined general psychological morbidity (Eslick & Talley, 2004b; Tew et al., 1995; White et al., 2008) and one studied panic disorder specifically (Fleet et al., 2003). The two cross-sectional studies (Eslick & Talley, 2004b; White et al., 2008) did not control for chest pain onset when examining predictors of retrospective health service use, thereby not distinguishing participants with recent onset chest pain who would be highly unlikely to have sought healthcare previously. This may explain the lack of association found by Eslick and Talley (2004b), and why White and colleagues (2008) found that presence of a psychiatric disorder was associated with increased healthcare use in the past year, but not healthcare use specifically for chest pain. An association was found for anxiety disorders, however (d=0.44), but not for mood disorders. Fleet and colleagues (2003) found a significant relationship between panic disorder and persistent health service use (χ^2=25.3, p<0.05) in their prospective study, but the analysis was restricted to use of the emergency room

and subsequent hospitalisations. The use of health service in other settings needs to be examined.

2.5.3 Heart-focused anxiety

Heart-focused anxiety is theorised to contribute to pain and drive medical evaluations. It is defined as "a specific fear of cardiac-related stimuli and sensations because of their expected negative consequences" (Hoyer et al., 2008). It is associated with appraising chest sensations as harmful, expecting negative consequences from cardiac activity, and showing persistent or exaggerated avoidance of activities believed to induce symptoms. Identifying benign symptoms as dangerous and associated anxiety-related responding is consistent with the theories of panic and anxiety sensitivity, which refers to the fear of anxiety-related symptoms (Eifert, Zvolensky, & Lejuez, 2000b). Where heart-focused anxiety differs from these concepts is that it is limited specifically to fear of heart-related sensations and functioning, and not to more generalised health concerns, such as with hypochondriasis (Eifert et al., 2000b). It could be argued that it is a specific form of anxiety sensitivity and/or hypochondriasis (Eifert & Lau, 2001; Eifert et al., 2000b).

Interviews with NCCP patients revealed that thoughts of death and fixation on the body were prominent and many patients abstained from physical activity due to uncertainty over how much exertion was possible (Jerlock et al., 2005). NCCP patients have been shown to have greater heart awareness, engage in more cardio-protective behaviour, and have greater conviction in having a cardiac disease than surgical inpatients and healthy controls (Eifert, Hodson, Tracey, Seville, & Gunawardane, 1996). Eslick and Talley (2004b) observed that anxiety was the main self-reported reason for seeking care for NCCP in the emergency room. They found that 78% of participants had sought healthcare for chest pain in the previous 12 months, and the main self-reported reason for seeking care was anxiety about symptoms (57%). Other reasons included chest pain severity and anxiety of potential serious disease. A qualitative study by Jerlock and colleagues (2005) corroborates the finding of a motive of relieving anxiety. In-depth interviews

revealed that the process of repeated investigation instilled feelings of safety and security.

As demonstrated by qualitative studies, heart-focused anxiety appears to be an important contributor to health service use, but quantitative studies examining its influence on outcomes are lacking. Zvolensky and colleagues (2003) found that heart-focused attention and fear of chest and heart sensations, as measured by the Cardiac Anxiety Questionnaire (Eifert et al., 2000a), were significantly related to chest pain severity at a cross-sectional level. However, this study included both cardiac and non-cardiac participants. Another study (Aikens, Zvolensky, & Eifert, 2001) examined fear of cardiopulmonary sensations specifically in NCCP patients, and found that it was cross-sectionally associated with chest discomfort intensity (labelled cardiac distress symptom score) (see Table 2.1). This factor needs to be examined prospectively, and its relationship to persistent health service use for chest pain, which it theoretically drives, needs to be determined.

A high prevalence of psychological morbidity is evident in NCCP, but further prospective studies are needed to examine its relationship to outcomes of persistent chest pain and persistent health service use. This would help to discern whether psychological factors are implicated in the aetiology of NCCP or whether they are co-morbid and/or maintaining factors.

Table 2.1 Studies examining predictors of persistent chest pain and persistent health service use

Authors	Year	N	Study details			
			Design	Measures	Key Findings	Comments/critique
Bass et al.	**(1983)**	46	Prospective cohort study of patients who had undergone cardiac catheterisation. **Outcome:** Chest pain	Physical symptom interview; Psychiatric interview; Social maladjustment & dysfunction.	At one-year follow up, the mean baseline psychiatric morbidity score of participants with chronic pain was higher than participants with improved pain (t=2.71, p<0.02). Participants with chronic pain were also more likely to have higher neuroticism scores (t=2.33, p<0.05) and have had chest pain for a longer period prior to recruitment (t=2.07, p<0.05).	The study included 15 participants with 'minimally diseased coronary arteries', 11 of whom were taking medication, who may differ from participants with normal coronary arteries. This study also has a small number of patients with chronic pain (n=19). The measures employed are unclear, particularly the measure of chest pain.
Beitman et al.	**(1991)**	72	Prospective cohort study of patients with normal coronary angiography. **Outcome:** Chest pain	SCID; SAS-SR; SAS; Medical and mental health service utilisation; Brief Symptom Inventory; Chest pain.	At 38-month follow-up, participants with panic disorder (50%) at baseline compared to those without, had a higher prevalence of chest-pain episodes (χ^2=9.24, p<0.01) and were more likely to believe that their symptoms were heart-related (χ^2=5.69, p<0.05).	It is unclear how chest pain was measured at follow-up and chest pain was not assessed at baseline.
Kisely et al.	**(1992)**	17	Prospective cohort study of patients with first time onset of NCCP recruited from coronary care unit/medical wards. **Outcome:** Chest pain	PAS; Social Stress and Support Interview; Health service use.	At 3-month follow-up, 12 (71%) had persistent pain but it is reported that there was no association between psychiatric disorder and continued chest pain.	No figures were provided to substantiate the claim that presence of a psychiatric disorder was not associated with persistent pain. A very small sample of 17 patients was examined. It is unclear how chest pain was measured.
Potts & Bass	**(1995)**	46	Prospective cohort of patients with normal or insignificantly narrowed coronary arteries on	CIS; Chest pain symptoms; Medical history during follow-up period;	At 11-year follow-up, 31 of the 42 surviving participants (74%) reported continued chest pain. Continued pain was associated with higher scores on the SCL-90R at follow-up.	No details were provided on how continued chest pain was associated with CIS scores at baseline. Participants who were told they had insignificantly narrowed coronary arteries

		coronary angiography. **Outcome:** Chest pain	SCL-90R at follow-up only; SCID at follow-up only.	Statistically significant differences were found for OCD, depression, psychoticism, somatisation and anxiety, in addition to the summary measures.	(n=15) were included in the analysis. These participants may differ to those with normal coronary arteries (n=31), if only in their perceptions and experiences.
Tew et al. (1995)	16	Prospective cohort study of patients attending an ED for the investigation of first-time chest pain. **Outcomes:** Chest pain & health service use	Chest pain; Health service use in last 6 months; Present State Examination (at 3-month follow-up).	Participants with a psychiatric disorder at 3-month follow-up, as determined by the Present State Examination, were more likely to have chest pain at 5-year follow-up. No statistical differences were found between participants with and without psychiatric disorders regarding healthcare utilisation.	Participants with ischemic heart disease and NCCP were analysed together, and only 16 out of the 59 participants included in the analysis had NCCP. It is unclear how chest pain was measured.
Aikens et al. (1999)	80	Cross-sectional study of patients presenting to an ED with chest pain. **Outcomes:** Chest pain & health service use	Panic (scale based on DSM-IV checklist); MI; BDI; ED utilisation; Prior exposure to other people's cardiac distress; Composite mean cardiac distress symptom score (composite score of presence & intensity of 6 cardiac sensations).	A regression model including panic symptoms, exposure to friends' cardiac distress and witness to others' cardiac distress explained 67% of the variance in cardiac distress symptom scores (R^2=0.67, p<.0001), while controlling for education, age, NCCP duration and number of illnesses. A regression model including cardiac distress symptom intensity, and exposure to siblings' and friends' cardiac distress explained 48% of the variance in ED utilisation (R^2=0.48, p<.001), while controlling for NCCP duration and age.	The authors concluded that prior exposure to cardiac distress of other people is likely to be significant in determining NCCP symptoms and ED utilisation, but variables examining exposure added very little variance explained to the model predicting cardiac distress symptom scores. Variables such as psychological factors like agoraphobic avoidance were excluded from models, likely due to high correlations between variables, yet the authors concluded that the variables did not contribute to predicting outcomes. Univariate analyses need to be presented. The stepwise forward selection regression techniques employed are also questionable.
Aikens et al. (2001)	63	Cross-sectional study of patients attending an Emergency Department (ED) with chest pain.	BSQ; Composite mean cardiac distress symptom score; DSM-IV checklist of panic	A hierarchical regression analysis including the dependent variables age, gender, number of illnesses, and the BSQ subscale score for fear of cardiopulmonary sensations, explained 34% of the variance in the	The use of the cardiac distress composite symptom score as the outcome is questionable. Fear of cardiopulmonary sensations is understandably related to current cardiac distress at cross-sectional

			Outcome: Chest pain	disorder criteria.	composite cardiac distress symptom score (p<0.001). This suggests fear of cardiopulmonary sensations may contribute to increased levels of chest sensations.	level. No univariate analyses were presented. One of the strengths of the study is that a number of other illnesses were controlled for.
Fleet et al.	**(2003)**	301	Prospective cohort study of patients attending an ED with chest pain. **Outcomes:** Chest pain & health service use	ACQ; MIA; BSQ; STAI; BDI; SCID (baseline only); Follow-up assessments: chest pain in past month and health service in past year for chest pain.	An average of 23 months after baseline assessment, panic disorder at baseline was significantly associated with the persistence of chest pain (x^2=17.3, p<0.05) and the number of ED consultations (x^2=25.3, p<0.05) and hospitalisations in the past year (x^2=16.4, p<0.05). Out of 82 participants with panic disorder, 57% had persistent chest pain and 40% re-presented to the ED. 31% of participants without panic disorder had persistent pain and 14% returned to the ED.	There was a low participation rate at follow up – 52% of initial sample completed follow-up questionnaires, but 70% completed telephone follow-up. The time to follow-up had a wide range from 11 to 39 months, which is likely to influence results.
Eslick & Talley	**(2004b)**	118	Cross-sectional study of patients attending an ED with chest pain. **Outcome:** Health service use	CPQ; EPQ; BAI; HADS.	Participants with acid regurgitation were more likely to have consulted medical practitioners in the previous 12 months at both univariate (OR=2.54, 95% CI 1.24-5.22) and multivariate level (OR=3.97, 95% CI 1.25-12.63). Heartburn and dysphagia, in addition to the psychological factors of anxiety, depression, and neuroticism, were not related to healthcare seeking behaviour.	Chest pain was not controlled for in the multivariate analysis although it was reported that chest pain frequency and severity was related to healthcare seeking.
Dammen et al.	**(2006)**	152	Prospective cohort study of patients referred to cardiac outpatient investigation for first-time evaluation of chest pain. **Outcomes:** Chest pain &	SCID; SF-MPQ; SCL-90-R; IAS; SF-36; Symptom attributions on 7-poing global rating scales; Chest pain improvement &	Participants with panic disorder were more likely to have persistent chest pain at follow-up compared to participants without panic disorder. Overall healthcare use did not differ between those with and without panic disorder at 1-year follow-up, yet participants with panic disorder were more likely to have	Figures and analyses distinguishing participants with and without CAD were not presented. It is unclear whether participants without further chest pain were included in the analysis of health service use at follow-up. Only p values were presented for the results of analyses, and no test statistics were

		health service use	health service use (at 1-year)	consulted their GP.	reported.
White et al. (2008)	229	Cross-sectional study of patients seeking evaluation in a cardiology department **Outcomes:** Chest pain & health service use	ADIS-IV-L; DASS; MPI; Healthcare Utilization subscale of the IAS.	44% of participants had a DSM-IV Axis I psychiatric disorder. Participants with at least one Axis I diagnosis reported higher pain severity on the MPI (*d*=0.74) and more frequent chest pain (*d*=0.60) compared with those without an Axis I diagnosis. When anxiety and mood disorders were examined separately, participants with anxiety disorders experienced more frequent chest pain than those without an anxiety disorder (*d*=0.63), but this association was not found for mood disorders. Presence of an anxiety disorder was associated with more medical visits for chest pain in the past year (*d*=0.44) but this association was not found for mood disorders.	The baseline interviews were conducted after participants were informed about their normal test results. This could influence participants' responses. In the examination of health service use, time of chest pain onset was not controlled for in the analysis, which is particularly important due to the cross-sectional design.

ACQ=Agoraphobia Cognitions Questionnaire; ADIS-IV-L=The Anxiety Disorders Interview Schedule for DSM-IV – Lifetime Version; BAI=Beck Anxiety Inventory; BDI=Beck Depression Inventory; BSQ=Body Sensations Questionnaire; CIS=Clinical Interview Schedule; CPQ=Chest Pain Questionnaire; DASS=The Depression, Anxiety, and Stress Scale; EPQ=Eysenck Personality Questionnaire; HADS=Hospital Anxiety and Depression Scale; IAS=Illness Attitude Scale; MI=Mobility Inventory for Agoraphobia; MIA=Mobility Inventory for Agoraphobia; MPI=The Multidimensional Pain Inventory; PAS=Psychiatric Assessment Schedule; SAS=Specific Activities Scale; SAS-SR=Social Adjustment Scale; SCID=Structured Clinical Interview; SCL-90R= Symptom Checklist-90 Revised; SF-MPQ= Short-Form McGill Pain Questionnaire; STAI=State-Trait Anxiety Inventory; SF-36=36-item Short-Form Health Survey

2.5.4 Cognitive factors

Beliefs, knowledge, and expectations profoundly influence bodily perception and have been found to influence satisfaction, reassurance, and future service use for a number of illnesses (Petrie & Pennebaker, 2004). Research has demonstrated that perceptions of cause strongly influence emotional response; perceived level of control influences adjustment; and perceived consequences are related to important outcomes such as adjustment, functional outcome, and return to work (Petrie & Pennebaker, 2004). Illness perceptions may be particularly relevant for determining outcomes in situations where patients are waiting lengthy periods prior to diagnostic testing and/or receiving test results. During these periods, negative beliefs about their symptoms could form (Nijher, Weinman, Bass, & Chambers, 2001).

Misattribution of pain to a cardiac cause was recognised as early as 1941 when it was concluded that patients with unexplained chest pain tended to "a misinterpretation of emotional symptoms ... [and] ... a conviction that the heart is to blame" (Wood, 1941, as cited in Mayou & Sharpe, 1997). Theory and data suggest that cognitive misinterpretation of somatic symptoms of anxiety leads to inappropriate illness behaviour, which thus reinforces somatic focus and mediates pain tolerance/threshold (Schwartz et al., 1999). In general, negative illness perceptions are associated with increased healthcare use and poorer recovery independent of measures of illness severity (Petrie & Weinman, 2006). In a study of over 1,000 general practice patients, a strong illness identity, a belief pain would last a longer time, and greater perceived consequences from their condition were associated with future healthcare use, independent of the doctors' rating of the severity of their health problem and previous healthcare use (Frostholm et al., 2005).

The significance of illness perceptions in NCCP has been demonstrated by Donkin and colleagues (2006) who found that they predicted patients' reassurance levels after normal exercise stress test results. Perceptions examined included: "what are

the consequences of the illness"; "how long it will last"; "how much control do I have over it"; "how well do I understand it"; and "how much does it affect me emotionally". At one month follow-up, all illness perceptions with the exception of illness understanding (i.e. how well participants understood their illness) were significantly correlated with reassurance, with Pearson r's ranging from 0.25 to 0.41. Participants who believed their chest pain would last a longer time; it was associated with greater consequences; they had little control over it; and were more emotionally affected by it, were less likely to be reassured. In hierarchical regression analyses controlling for health anxiety and state anxiety, the perceptions of timeline and treatment control made unique contributions to the model, predicting 31% of the variance in reassurance scores at follow-up. Measuring illness perceptions prior to receiving diagnostic test results is a useful method of identifying patients with negative perceptions who may be likely to have poor outcomes. Longer follow-up periods are needed, however, and the relationship between reassurance and persistent pain and health service use needs to be determined. Although reassurance is theorised to contribute to continued pain, disability, and service use (Bass, 2007; Schwartz et al., 1999), this has not been empirically investigated.

2.6 Social factors

The personal understandings that are used to interpret embodied sensations are socio-culturally informed and dynamic (Hay, 2008). Bass (2007) claims that previous experience, such as exposure to family members or others with heart disease, is a crucial factor for determining the way in which sensations are interpreted. A qualitative study with 40 patients with familial hypercholesterolemia (FH) found that perceived vulnerability to heart disease was grounded in perception of genetic and inherited risk (Frich, Ose, Malterud, & Fugelli, 2006). In another qualitative study of seven participants which also explored FH in patients being treated for FH (Senior, Smith, Michie, & Marteau, 2002), participants displayed vigilance to symptoms possibly indicating a heart attack, and cardio-protective behaviour such as eating a diet low in fat. Although participants appeared to feel in control of their

risk of heart disease, they nevertheless were engaged in activities to minimise their risk. These results points to the importance of perceived vulnerability to heart disease, based on socio-cultural factors.

In Jerlock and colleagues' (2005) qualitative study, many participants reported having relatives who had died of a myocardial infarction, which increased their fear. In addition, symptoms or patterns which are easily recognised as threats have been found to prompt earlier help seeking (Petrie & Pennebaker, 2004). Therefore, greater exposure to heart disease may result in more heart-focused interpretations and illness behaviour (Zvolensky, Feldner, Eifert, Vujanovic, & Solomon, 2008).

One study has examined the relationship between exposure to family and friends with heart disease and chest discomfort intensity (labelled cardiac distress symptom intensity) and emergency department utilisation, in a cross-sectional study of patients presenting to an emergency department with chest pain (see Table 2.1) (Aikens et al., 1999). The results indicated that exposure to siblings and friends with heart disease may be associated with more intense chest discomfort as well as greater utilisation of the emergency department in the past for chest pain. There were a number of limitations to the study however, (see Table 2.1 for details) and further research is needed.

If an association exists, this has implications for public awareness campaigns for cardiovascular disease. The recent National Cardiovascular Health Policy (Department of Health & Children, 2010) recommends the promotion of symptom awareness and appropriate emergency responses to potential cardiovascular symptoms through the use of media and education campaigns. While it is extremely important for people with cardiovascular disease to seek care as early as possible, public awareness campaigns may result in increased exposure to heart disease and could result in an increase of NCCP presentations. Prospectively examining the influence of exposure to heart disease on outcomes for NCCP patients could help to inform health promotion strategies.

2.6.1 Service-related factors

Service-related factors which may contribute to the maintenance of NCCP include the prescription of anti-anginal medications before diagnostic testing, use of a probable diagnostic cardiac label, lack of explanation for distressing and continuing symptoms, lack of communication leading to contradictory and conflicting advice, or inconsistent or ambiguous information (Bass & Mayou, 2002). In a questionnaire follow-up cohort study by Spalding and colleagues (2003), many patients commented that the outlook for their condition had not been discussed and that any prognosis given was often inaccurate. It was further claimed that physicians underestimated both the duration and frequency of recurring symptoms. The immediate viewing of chest pain patients through a life-threatening cardiac lens is also likely to shape perceptions, and some patients may gear their lifestyle to a perceived cardiac diagnosis prior to diagnostic testing.

Cardiac testing has been theorised to engender rather than alleviate distress. In a study examining anxiety levels in patients as they awaited elective coronary angiography (De Jong-Watt & Arthur, 2004), moderate levels of anxiety were detected during the waiting period, and levels increased as participants approached their procedure date. The authors concluded that support should be provided to patients awaiting elective procedures. Although a potentially life-threatening condition must not be overlooked, excessive anxiety over a condition that may not exist should be minimised. Service-related factors are theoretically related to poorer outcomes in NCCP patients, but the association has not been empirically examined. Evidence on the potential impact of service-related factors on outcomes is needed in order to inform the management of NCCP patients.

2.7 Summary

Numerous factors have been implicated in poor outcomes for NCCP patients, but they are poorly understood. Nevertheless, it is increasingly believed to be caused by an interaction between physical and psychological factors. A biopsychosocial model

proposed by Bass and Mayou (Bass & Mayou, 2002) incorporates physical, psychological, and social factors to account for persistent symptoms and related disability. While physical and psychological factors have been examined in NCCP, very little research has prospectively examined their relationship to poor outcomes in NCCP, and many limitations to the research have been highlighted. Cognitive and social factors have been relatively neglected, and while theoretical associations have been made, evidence is needed to support them. In addition, factors tend to be studied in isolation and have not been integrated, despite the increasing recognition that NCCP is a multi-factorial condition.

Chapter 3: Management of NCCP

3.1 Introduction

The complexity in diagnosing and understanding predictors of poor outcomes in NCCP patients has been discussed in the previous chapters. The management of NCCP is thus very challenging. This chapter considers the challenge of medical uncertainty and more specifically, it examines some approaches to the management of NCCP.

3.2 Managing uncertainty

There is little consensus about the aetiology of NCCP to guide its management. Medical professionals face a number of challenges in ascertaining a differential diagnosis and in dealing with the complexity of the condition. Firstly, they must ensure that a potentially serious condition is not overlooked, while being careful not to create excessive anxiety (Schwartz & Bourassa, 2001, p. 1825). Once they are reasonably assured that a cardiac cause has been excluded, they are faced with uncertainty. Uncertainty is an intrinsic element of medical care (Arrow, 1963; Fox, 1980; Hatcher & Arroll, 2008). Yet both physicians and patients are relativity intolerant of it. Patients expect to receive a diagnosis once they have been thoroughly assessed, and a lack thereof can cause mutual frustration (Luther & Crandall, 2011). Doctors are tasked with striking "a balance between appropriate investigation, explanation and reassurance, and over-investigation with the risk of iatrogenic harm" (Hatcher & Arroll, 2008).

Symptoms are commonly medically unexplained (Hatcher & Arroll, 2008; Kisely & Simon, 2006). Between 20-50% of patients presenting with somatic symptoms do not have a detectable organic cause (Kisely & Simon, 2006; Reid et al., 2002). These patients are sometimes referred to, somewhat disparagingly, as the 'worried well', but evidence suggests that these patients have similar if not higher rates of

functional disability than patients with medically explained symptoms (Dwamena, Lyles, Frankel, & Smith, 2009; Kisely & Simon, 2006).

3.2.1 Uncertainty from the doctor's perspective

In a survey of primary care practitioners, practitioners reported being generally sympathetic to patients with medically unexplained symptoms, but found these patients difficult to help, and often a source of stress (Dowrick et al., 2008). Some doctors also complain that unexplained symptoms are not legitimate demands on their time (Salmon, 2007). Intolerance to uncertainty has been shown to relate to an increase in test-ordering tendencies and failure to comply with evidence-based guidelines (Ghosh, 2004). For example, in a study of risk-aversion and associated medical costs, a one standard deviation increase in a measure of risk-aversion in family physicians generated a 3% increase in test referral costs, after adjusting for case mix (Fiscella et al., 2000). Not only is uncertainty costly in an economic sense, but also to the individual who may be adversely affected by unnecessary tests and treatments (Luther & Crandall, 2011).

3.2.2 Uncertainty from the patient's perspective

In a qualitative study with patients with medically unexplained symptoms, participants referred to themselves as "fraud," "time waster," "hysteric," and "fake" (Nettleton, 2006). Some have felt rejected, ignored, belittled, and blamed for their symptoms (Werner & Malterud, 2003). A lack of explanation for their symptoms leaves them in "diagnostic limbo" (Nettleton, Watt, O'Malley, & Duffey, 2005). Petrie and Weinman (2006) theorise that there is a pressure on patients to find a label for their ill health but due to lack of medical knowledge, they are limited in their ability to build a cognitive model of explanation. Healthcare use is likely to be continued until they have a satisfactory cognitive model or explanation that enables them to interpret their symptoms differently (Petrie & Pennebaker, 2004). Salmon and colleagues (1999) found that patients with medically unexplained symptoms were most satisfied with their healthcare consultations if an explanation made sense, blame was removed from them, and ideas were generated on successful management of the condition.

3.3 Treatment

Despite the limited understanding of NCCP, and the uncertainty facing physicians and patients, a number of different treatments for NCCP patients have been provided, even cardiac rehabilitation (e.g. Asbury et al., 2008). Most studies have examined the effectiveness of medication and psychological interventions.

3.3.1 Medication

NCCP appear to be commonly treated with medication for gastro-oesophageal causes. In a national survey of 246 cardiologists in the United States (Wong et al., 2005b), proton pump inhibitors were the most commonly used therapeutic modality (45%), followed by lifestyle modifications (29%), and H2 blockers (12%). Proton pump inhibitors and H2 blockers are both medications used to treat gastro-oesophageal reflux disease (GERD). However, there are very few high-quality trials examining the effectiveness of GERD treatment in NCCP, as acknowledged by a recent systematic review (Hershcovici, Achem, Jha, & Fass, 2012). Most studies reviewed were of questionable quality and were not double-blind, placebo-controlled. The authors of the review concluded that proton pump inhibitors were effective in treating NCCP, and despite the acknowledged limitations, they concluded that all NCCP patients should be treated for GERD, unless a specific alternative diagnosis is indicated.

This conclusion does not appear to be substantiated and may reflect the bias of gastroenterologists studying this condition. Interventions with medication for gastro-oesophageal causes have included participants in whom there is no evidence of any gastro-oesophageal disorder, as demonstrated by endoscopies and oesophageal pH monitoring (e.g. Kim et al., 2009). High-quality, strictly controlled trials are also lacking for anti-depressant treatment. Anti-depressants have shown positive effects, yet substantial limitations to trials have been identified in two recent systematic reviews of NCCP treatment (Nguyen & Eslick, 2012; Wang et al., 2012). Not only is further research on medication interventions needed, but the appropriate patients for interventions need to be identified, since NCCP is not a

homogenous condition. The acceptability of medication to patients also needs to be considered. In an intervention trial, nearly 80% of NCCP patients declined to participate due to the potential for being randomised to receive medication (Spinhoven, Van der Does, Van Dijk, & Van Rood, 2011).

3.3.2 Psychological interventions

Due to the high levels of psychological co-morbidity and the theoretical importance of cognitions in NCCP, psychological approaches have been developed. A Cochrane review (Kisely, Campbell, Skerritt, & Yelland, 2010) examined the effectiveness of psychological interventions for the management of NCCP and included ten RCTs, providing a range of interventions including cognitive-behavioural therapy (CBT), relaxation training, breathing re-training, hypnotherapy, and a brief intervention by a nurse. The interventions significantly reduced chest pain reporting in the first three months following the completion of interventions. The fixed effects relative risk was 0.68 (95% CI 0.57-0.81), and it remained significantly reduced up to nine months later (RR=0.59, 95% CI 0.45-0.76). Interventions also significantly reduced chest pain frequency and severity. While these results appear promising, conclusions on the effectiveness of psychological interventions need to be tentative. There was a great deal of heterogeneity in the studies examined, with a wide variety in type of intervention, outcome measurement, follow-up periods, and implementation of intervention.

As discussed in the previous two chapters, NCCP patients themselves are widely heterogeneous and numerous potential aetiologies and contributing factors can exist. In particular, varying levels of psychological morbidity can exist and these need to be accounted for. Three studies in the Cochrane review excluded participants who had a co-morbid psychiatric disorder (Klimes, Mayou, Pearce, Coles, & Fagg, 1990; Mayou et al., 1997; van Peski-Oosterbaan et al., 1999), yet these patients are perhaps most in need of psychological interventions. In addition to the wide heterogeneity in study design and patient type, all studies recruited patients from outpatient settings, and the results may not therefore be

generalisable to patients recruited from other settings such as the emergency department.

The systematic review concluded that while cognitive-behavioural and hypnotherapy interventions may be effective in the short-term, more research on psychological interventions is needed with longer follow-up periods and more rigorous designs (Kisely et al., 2010; Robertson, 2006). A more recent cognitive-behavioural intervention compared antidepressant medication to CBT, and demonstrated the promise of targeting heart-focused anxiety (see section 2.5.3) (Spinhoven et al., 2011). The RCT compared 12 sessions of CBT (n=23) to the medication paroxetine (a selective serotonin reuptake inhibitor (SSRI)) (n=23) and to placebo (n=23). Intention-to-treat analysis demonstrated that CBT was significantly superior to placebo and to the medication paroxetine in reducing NCCP at post-treatment. CBT was effective in modifying heart-focused anxiety, which predicted reduced NCCP. Further research comparing interventions over longer follow-up periods is needed in order to discern the types of intervention which are most effective, and for whom.

Not all NCCP patients are interested in receiving psychological interventions. In a survey of 778 NCCP patients discharged from cardiac clinics, 64% of patients with persistent chest pain indicated an interest in psychological treatment (Van Peski-Oosterbaan, Spinhoven, Van Der Does, & Bruschke, 1998). Males, younger respondents, and participants with a higher degree of pain limitation were more likely to indicate an interest. The difficulty in recruiting eligible participants to psychological interventions also raises questions about the acceptability of psychological treatments. In the Cochrane review (Kisely et al., 2010), only half of the ten studies reported on their participation rates. In studies where participation rates were reported, they varied from 40-60%. Although completion rates were generally acceptable at approximately 80%, in two cases, over 35% of participants were lost to follow-up (DeGuire, Gevirtz, Hawkinson, & Dixon, 1996; Mayou et al., 1997). Patients may feel their concerns about pain and the medical context in

which they present are not being adequately addressed through psychological explanations of symptoms (Mayou, Bass, & Bryant, 1999).

Evidence on the treatment for NCCP is limited to small trials of questionable quality, and research needs to discern what types of interventions are effective and acceptable to patients (Robertson, 2006), and which patients would benefit the most. It is claimed that psychological interventions should be considered for patients, particularly if symptoms are associated with abnormal health beliefs, depressed mood, panic attacks, or other symptoms including fatigue or palpitations (Bass, 2007). A difficulty with psychological interventions is that they are costly and require expertise that many physicians managing NCCP do not have. In the Cochrane review of psychological interventions (Kisely et al., 2010), all studies were individual interventions, with the exception of one group intervention (Potts, Lewin, Fox, & Johnstone, 1999), and were primarily conducted by psychologists. More cost-effective interventions need to be considered.

3.3.3 Improved communication

Simple advances can be made in everyday clinical practice to help improve outcomes. Factors implicated in negative outcomes for NCCP patients such as negative perceptions and lack of reassurance about the heart can be targeted through improved communication with patients. The probable explanation of what underlies the symptoms should be presented in a tangible way, and inconsistent and ambiguous information should be avoided (Mayou et al., 1999; Mukerji, Beitman, & Alpert, 1993; Salmon et al., 1999). Effort should be made to give a more precise diagnosis where a defined cause cannot be established. It is also recommended that patients are clearly informed why more tests are not being carried out, despite the lack of a specific diagnosis (Ågård et al., 2005). Patients' beliefs, exaggerated fears of death, marked conviction of disease, or intense bodily preoccupations need to be elicited (Jerlock et al., 2005). It is proposed that interventions aimed at reassuring patients with NCCP have been unsuccessful due to difficulty in assimilating reassuring messages, which is attributable to a discrepancy with established beliefs. Sanders et al (1997) consider that their

individualised intervention involving information, advice, and a forum for discussion by a specially trained cardiac nurse, was ineffective due to the lack of preparation for negative findings. By involving patients in discussions about their own beliefs and fears regarding their symptoms, patient satisfaction and well-being may be increased (Ågård et al., 2005). Although no organic cause can be determined, the experience of illness should not be rejected or denied.

Petrie and colleagues (2007) tested whether providing prior information about the meaning of normal results led to better assimilation. They found that participation in a discussion group and/or the provision of a simple pamphlet significantly improved reassurance. At one month, 69% of patients were reassured in the discussion group compared with 40% in the pamphlet group and 35% in the control group. It was concluded that time spent explaining the meaning of normal test results is likely to increase patients' reassurance and subsequently reduce anxiety and future service use. Yet the impact on persistent pain and future anxiety and service use was not examined.

More recently, Arnold and colleagues (2009) tested the impact of the provision of information sheets to patients with chest pain and suspected acute coronary syndrome. Patients were randomised to a control group receiving standard verbal advice (351 participants) and an intervention group receiving verbal advice followed by an information sheet (394 participants). One of four information sheets was distributed according to four possible diagnostic categories: 1) benign non-cardiac chest pain (23%); 2) chest pain uncertain, no follow-up (65%); 3) chest pain uncertain, referred to cardiology (9%); and 4) angina (3%). The first information sheet contained reassurance about the heart, provided some potential explanations for benign chest pain, and offered advice on symptom management including exercise, relaxation, controlled breathing, and managing worrying thoughts. The second and third information sheets also provided advice on symptom management and explained the meaning of the test results, but did not contain conclusive reassurance about the heart. At one month follow-up, those receiving information sheets had lower mean HADS scores for anxiety (7.61 vs. 8.63,

difference 1.02, 95% CI 0.20-1.84) and depression (4.14 vs. 5.28, difference 1.14, 95% CI 0.41-1.86), and higher scores for mental health and perception of general health on SF-36. The number needed to treat[1] to avoid one case of anxiety was nine (95% CI 5.0-46.1) and the number needed to treat to avoid one case of depression was 13.1 (95% CI 6.6-∞).

However, the information sheet had no significant effect on frequency or severity of further pain, plans for changes to lifestyle, subsequent information-seeking behaviour, planned actions in response to further pain, or satisfaction with care. It is possible that improvements were not seen in these outcomes due to the majority of patients receiving information sheets on the basis of a diagnosis of pain of uncertain cause suitable for expectant management. As 228 patients out of 349 in the intervention group were placed in this category, it is possible that advice based on expectant management is less reassuring than the advice based on a benign non-cardiac cause. Sub-group analyses were not presented in this study but would be worthwhile exploring. Nevertheless, the study provides promising results for the simple and inexpensive intervention of providing an information sheet. More evaluation of information sheets relating to cardiac diagnostic assessment is needed. In addition, further research on how patients' experiences with health services can influence their outcomes is needed, such as how they impact upon their reassurance and illness perceptions. Interventions can then be designed to target these factors.

3.3.4 Individualised care

Due to the heterogeneity in NCCP, an individualised, 'stepped' approach to the management of NCCP has been recommended (Chambers & Bass, 1998; Mayou & Thompson, 2002; Schwartz et al., 1999). Interventions need to be tailored to the individual causes of NCCP, and this needs to be determined prior to delivering the interventions (Mukerji et al., 1993). However, as discussed in Chapters 1 and 2, this is no easy feat. Greater understanding of NCCP is needed so that appropriate,

[1] The number need to treat (NNT) is the average number of patients who need to be treated to prevent

acceptable interventions that are tailored to the individual needs of patients can be developed. Prospective studies are needed to determine factors likely to influence persistent pain so that these patients can be targeted. NCCP may be more likely to resolve in particular patients. Patients who are more likely to persist in using health services for the investigation of chest pain also need to be identified. Understanding the motivations and causes of persistent service use could aid in the development of interventions aimed at minimising the cost of repeated investigation.

3.4 Summary

The management of NCCP is a complex issue. The uncertainty surrounding the cause of NCCP is a source of distress to both physicians and patients. A number of approaches to its management have been examined including pharmacotherapy, cognitive-behavioural therapy, and targeting cognitions through improved communication. Further understanding is needed before optimal interventions can be developed, but it appears that individualised, multi-dimensional approaches are needed. They have the potential to improve outcomes and reduce the high costs associated with repeated use of health services, which are already struggling to manage resources effectively (Dammen, Ekeberg, Arnesen, & Friis, 1999; Eslick, Coulshed, & Talley, 2002; Robertson, 2006).

Chapter 4: The Current Study

4.1 Introduction

The preceding chapters provided an overview of the potential aetiology of NCCP, predictors of poor outcomes, and approaches to the management of this symptom. Examination of the literature highlighted the lack of understanding of NCCP and the reasons behind poor outcomes. In particular, there is a dearth of research examining why a high proportion of patients continue to experience chest pain and return to health services for the investigation of their pain. An enhanced understanding could inform the effective management of these patients. This chapter presents the rationale, aims, theoretical framework, and design of the current study.

4.2 Study rationale

A comprehensive understanding of NCCP eludes research and clinical communities. As discussed in Chapter 1, many factors have been implicated in the aetiology of NCCP, while many limitations in the literature have been highlighted. Studies employ differing definitions, recruitment settings, and inclusion criteria, for example. This chapter also highlighted the poor outcomes of NCCP patients. In particular, chest pain and related health service use have been shown to persist in a large proportion of patients. Chapter 2 explored the potential contributors to continued symptoms and service use. Physical, psychological, and social factors have been associated with outcomes, but there is a dearth of research examining these associations. Studies also tend to be conducted within individual disciplines, and few prospective, cross-disciplinary studies have been carried out. Biopsychosocial explanatory models have only emerged in the last decade and need to be developed.

Interventions for NCCP patients were explored in Chapter 3. While pharmacological and psychological therapy trials have demonstrated some benefit, interventions have been heterogeneous and of questionable quality. In addition, the acceptability of interventions by NCCP patients needs to be further explored due to low rates of participation. Further conceptual and analytic work is needed in order to design successful and feasible interventions and management guidelines. Through enhanced understanding of predictors of poor outcomes in NCCP, interventions can be targeted effectively and appropriately. Insight into how patients perceive and monitor their body is also needed, while recognising that perceptions and behaviours are shaped in a cultural and social context (Jerlock et al., 2005). Recommendations can then be made on the structuring of care to address the psychosocial aspects of chest pain. Hopefully, this may provide considerable health and economic gains.

4.3 Theoretical framework

The theoretical framework for the study was informed by the biopsychosocial model of NCCP developed by Bass and Mayou (2002) (see Figure 2.1). Bass and Mayou propose that NCCP is best understood as an interaction between normal or abnormal physiological processes (e.g. gastro-oesophageal cause), psychological factors (e.g. anxiety), and social factors (e.g. doctors' reactions). They emphasise the importance of the interpretation of the pain in determining persistent symptoms and related disability. In this respect, it can be said to compliment Leventhal's self-regulatory theory (Petrie & Pennebaker, 2004), which proposes that patients have cognitive and emotional reactions to symptoms that influence patient outcomes. However, this study did not examine coping, which is theorised to act as a mediator between illness perceptions and outcomes in Leventhal's model.

4.4 Aims and objectives

The central aim of the study was to explore the role of physical, psychological, and social factors in the persistence of NCCP and related health service use.

The objectives were:

(1) to estimate the proportion of patients in an Irish context who receive normal stress test results in a major, acute hospital, but continue to experience pain and use medical services for chest pain one year later;

(2) to investigate the predictive value of baseline physical, psychological and social factors in predicting the outcomes of persistent chest pain and persistent health service use in patients with NCCP;

(3) to gain a greater insight into patients' experiences and beliefs, and how these were influenced by their interactions with health services;

(4) to develop evidence-based recommendations for appropriate interventions and management.

4.5 Study design

Due to the complex, multi-factorial nature of NCCP, a mixed methods research design was chosen. The central premise of mixed methods research is that the combination of quantitative and qualitative approaches facilitates a better understanding of a research phenomenon than either approach in isolation (Creswell & Plano Clark, 2007). The complexity of most research phenomena necessitates multiple forms of evidence (Creswell & Plano Clark, 2007). In addition, the combination of both approaches can offset the weaknesses of either approach. It is difficult to explore context and setting in quantitative research and the voice of participants can be lost. Qualitative research, on the other hand, has been criticised

for its lack of generalisability and its subjective interpretations. Mixed methods research offers strengths that offset these weaknesses (Creswell & Plano Clark, 2007).

There are many different research designs within mixed methods research to choose from (Tashakori & Teddlie, 2003). An Explanatory Sequential Design, developed by Creswell and Plano Clark (2007), was chosen as the optimum design. The design starts with the collection and analysis of quantitative data, which is followed by the subsequent collection and analysis of qualitative data. The qualitative data builds upon the initial quantitative results.

A prospective cohort study was initially conducted in order to examine the predictive value of variables measured prior to cardiac testing on one-year outcomes of patients with normal test results. Physical, psychological and social variables were all investigated. A one-year follow-up period was chosen since research on long-term outcomes is lacking, and the time period allowed both for sufficient time for the detection of non-transient symptoms and for patterns of healthcare seeking behaviour to be detected. The follow-up period was also chosen for practical reasons. The results of the quantitative study were used to inform the selection of participants for the qualitative study. Six participants who continued to experience chest pain one year later were interviewed, and the data were collected and analysed according to the principles of Interpretative Phenomenological Analysis (see Chapter 9 for more details). The interviews explored how participants made sense of their symptoms in the context of normal test results, and examined how their experiences with the health services influenced their experience of chest pain. The qualitative findings enhanced understanding of the processes involved.

The following chapter presents the research methodology for the prospective cohort study.

Chapter 5: Prospective Cohort Study - Methodology

5.1 Introduction

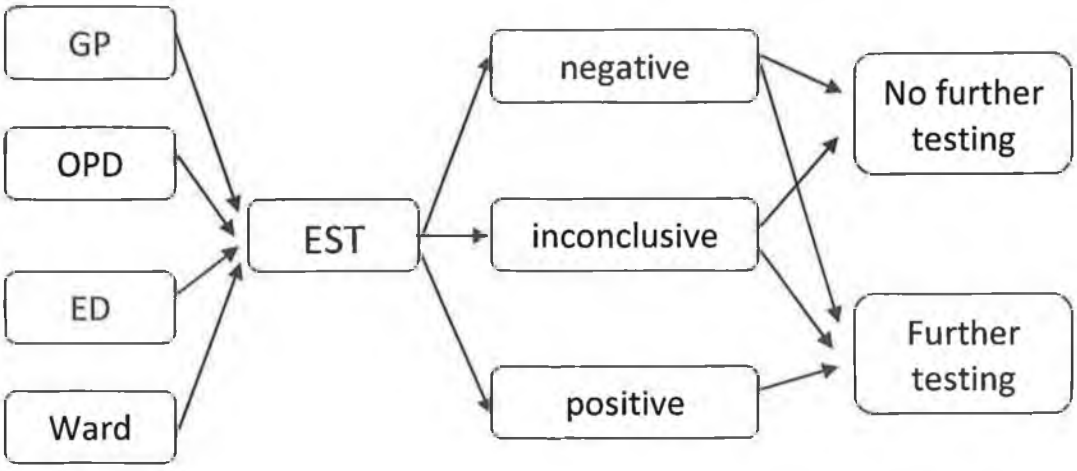
This chapter presents the methodology of the prospective cohort study, which examines the persistence of NCCP and related health service use in patients with normal cardiac test results. Details on the recruitment, assessment procedure, measures, and the methods of analysis will be provided.

5.2 Participants

5.2.1 Selection and recruitment

Consecutive patients referred for diagnostic exercise stress tests between April and December 2009 at a major, acute, academic teaching hospital were invited to participate in the study. This hospital has a local community of approximately 250,000 people and about 30% of patients are from non-catchment areas (Beaumont Hospital, 2010). Both outpatient and inpatient referrals were included in the sampling frame (see Figure 5.1). Outpatients were referred by their general practitioner (GP) or by outpatient departments (OPDs), and typically waited four months for their test. Inpatient referrals included patients admitted to a ward and those referred directly from the emergency department (ED).

Referral for an exercise stress test (EST) was chosen as an entry point to the study since a larger and more representative sample of NCCP patients could be captured than sampling patients referred straight to angiography, who have a higher risk of CAD. Although some participants with normal test results may have undetected CAD or CAD patients may be given falsely negative results, a coronary angiography is not performed routinely on low-risk patients (Dammen et al., 2006).



GP=General Practitioner; OPD=Outpatient Department; ED=Emergency Department

Figure 5.1 Sampling frame and patient journey

5.2.2 Inclusion criteria

Selection of participants was based on the fulfilment of inclusion and exclusion criteria and on agreement to participate. Participants satisfied the following inclusion criteria:

- referred for diagnostic exercise stress test
- symptoms of chest pain
- aged ≥ 18 years
- ability to communicate in English

5.2.3 Exclusion criteria

Patients were excluded according to the following exclusion criteria:

- documented history of heart disease evidenced by coronary angiography, exercise testing and/or enzyme examination
- mitral valve prolapse evidenced by auscultation and echocardiography
- too ill or distraught to participate, as determined by medical staff
- diagnosis of dementia or psychiatric condition, which would preclude competent participation, as determined by medical records where available

- hospital employee
- lack of consent

5.3 Sample Size

Due to the dearth of research on predictors of persistent chest pain and persistent health service use, a pragmatic approach to calculating the sample size was taken. A sample size calculation estimated that a sample size of 120 NCCP patients would be required to have 80% power with an alpha (α) of 0.05 to detect a difference of 25% in the persistence of noncardiac chest pain between participants with and without an anxiety disorder, assuming that 55% of participants with an anxiety disorder have persistent pain (i.e. 55% versus 30%). The estimation is based on findings of a prospective cohort study of NCCP patients (Fleet et al., 2003) (see Table 2.3 for details). Allowing for an attrition rate of 20%, based on the attrition rate of 16% of a study of similar scale and timeframe (Dammen et al., 2006), a sample of size of 144 patients with NCCP was sought. Since it was estimated that approximately 25% of participants would be excluded due to a cardiac diagnosis, a total sample size of 180 was determined.

5.4 Procedure

In order to identify potential inpatient participants, inpatient referral forms were checked daily in the ECG department. All referrals for an EST in the hospital were sent and collected here. The medical records of these patients were then checked to see if they satisfied inclusion criteria. If suitable, patients were approached and informed about the study and the procedure involved. They were also given an opportunity to ask about any concerns or queries. If agreeable, they were given a copy of the information leaflet (Appendix B), consent form (Appendix D), and pre-testing questionnaire (Appendix E). They were asked to read the information leaflet, and if they were still interested in participating, they were instructed to complete the consent form and questionnaire. After an hour, they were approached again and asked whether they had any questions or difficulty in

completing the questionnaire. Where required, assistance was given and the researcher administered the questionnaire as an alternative to self-completion in the case of illiteracy or visual impairment.

For the recruitment of outpatients, outpatient referral forms were inspected three weeks before scheduled appointments. The reason for the referral was examined and patients were excluded according to inclusion and exclusion criteria. Eligible patients were posted a pack including a letter of invitation (Appendix A), information leaflet (Appendix C), consent form (Appendix D), and pre-testing questionnaire (Appendix E). The letter of invitation explained that they would be contacted by telephone by the researcher after ten days to explain the study and discuss any queries. If they did not wish to be contacted, they were asked to email or ring the ECG secretary whose contact details were provided. If no contact was made within a ten day period, the researcher telephoned the patient and, if agreeable, the patients were asked to bring the completed consent form and questionnaire with them to their EST appointment. If assistance was needed to complete the documents, an arrangement was made to meet with them before their appointment.

On the day of the appointment, the researcher greeted patients who had indicated agreement to participation when they arrived for their appointment. They were asked if they had brought the completed questionnaire and any queries were answered. If they did not bring a completed questionnaire but still wished to participate, the questionnaire was re-distributed and, where time allowed, was completed prior to their EST. Where time was insufficient, the completion of the measures of illness perceptions and attributions were prioritised for completion prior to testing, as these were most likely to alter following testing. The remaining sections were completed after their EST. Participants were also asked questions regarding their health service use while waiting for their test appointment or immediately afterwards (see Appendix F).

All participants were re-contacted one year later and were posted a follow-up invitation letter (Appendix G), follow-up questionnaire (Appendix I), and a stamped addressed envelope in which to return completed questionnaires. Participants who had returned questionnaires were telephoned and thanked, and further details on health service use were obtained (see Appendix J for telephone questionnaire). For those who had not, the questionnaire and stamped addressed envelope was re-sent approximately two to three weeks later along with a reminder letter (Appendix H). In addition, these participants were telephoned to remind them to return the questionnaire, and the primary outcomes of persistent pain and health service use were assessed over the telephone to circumvent missing data on primary outcomes for non-respondents (see Appendix J). These participants were also asked whether they had received the results of their EST and/or an explanation for their pain so that service-related issues could be established. After these questions were completed, they were asked whether they had received the questionnaire in the post and whether they had any queries about it. If they claimed they had not received it, their address was checked, and the questionnaire was re-sent. It was explained that the return of the follow-up questionnaire was entirely voluntary, but that their participation was greatly appreciated. Any queries were answered and assistance was provided where needed. Participants who were not contactable were telephoned 20 times before they were considered non-respondents. Telephone numbers that were out of service were checked against hospital electronic records in case any telephone numbers had been updated.

Hospital electronic records were consulted at one-year follow up to determine the result of the exercise stress test and any other diagnostic tests. Participants in whom a cardiac diagnosis had been excluded were classified as NCCP. Both participants with cardiac and non-cardiac results were assessed at one-year follow-up, but only NCCP patients are reported on in this thesis.

5.5 Baseline measurement

The theoretical framework of the study guided the selection of constructs to be measured. Previous research as outlined in chapters 1 through 3 guided the selection of measurement tools. The questionnaire comprised of 18 domains in 9 sections as summarised in Table 5.1 on page 64 in their order of appearance. Information on the measurement tools and their respective item numbers are exhibited. To aid inspection of the questionnaire, which can be found in Appendix E, the section letters and question numbers are also provided.

5.5.1 Chest pain

The frequency, duration, and severity of chest pain were measured using questions from the Chest Pain Questionnaire (CPQ), which was developed by Eslick and Talley (Eslick & Talley, 2004a). The CPQ is a validated measure of symptoms over the previous 12-month pre-survey period. The word "pain" was replaced with "discomfort" as recommended by Gallagher and colleagues in their study of chest symptoms following coronary stenting (2008). The experience of chest pain can vary greatly and has been described by patients with a wide range of descriptive terms including 'aching', 'tightness', 'pressure', 'sharpness' and 'tingling' (e.g. McSweeney et al., 2003). Many may therefore consider the term "discomfort" more applicable to their symptom experience. Frequency was rated on a 7-point Likert scale ranging from "none" to "daily." A 4-point scale was used to assess discomfort severity using the following categories: mild, moderate, severe, and very severe. The typical duration was measured on a 6-point scale ranging from "less than 1 minute" to "more than 1 hour." These baseline measures were treated as ordinal variables.

5.5.2 Illness characteristics

Detail on when participants' symptoms began was gathered using a question from the CPQ (Eslick & Talley, 2004b) with eight categories ranging from "in the last 3 months" to "more than 20 years ago." Participants were also asked how long they had been waiting for their EST in an open-ended question. This information was

also obtained from the dates recorded on referral forms. Where dates had not been recorded, participant estimates were used.

5.5.3 Musculoskeletal pain

In order to assess musculoskeletal-like chest pain, participants were asked to identify ("yes" or "no") whether their pain was worsened by the following movements: moving arms, rolling over in bed, bending over, bending sideways, walking, and running. In addition, they indicated whether taking a deep breath and/or coughing worsened symptoms. These questions were derived from the Chest Pain Questionnaire (Eslick & Talley, 2004b). Participants who answered "yes" to any of these questions were classified as having musculoskeletal-like chest pain, i.e. their pain worsened on moving, breathing, or coughing.

5.5.4 Interference

Pain limitation was assessed using Question 9 of the short form of the Brief Pain Inventory (BPI-SF) (Cleeland & Ryan, 1994). This is a widely used measure of the reactive dimension of pain using 7 numeric 11-point scales. It has been shown to correlate highly with pain intensity (Von Korff, Jensen, & Karoly, 2000). Although originally designed for use with cancer patients, it has been validated as a measure with a wide range of pain patients (Keller et al., 2004). Participants were asked to rate from 0 (no interference) to 10 (interferes completely) the degree to which pain interfered with their general activity, mood, walking or other physical activity, work, relations with others, sleep, and enjoyment of life. Scores were added to provide a total interference score with a possible range of 0 to 70. Higher scores indicated higher interference levels.

5.5.5 Heart-focused anxiety

Heart-focused anxiety was measured using the Cardiac Anxiety Questionnaire (CAQ) (Eifert et al., 2000a). This questionnaire has demonstrated good internal consistency and convergent validity with both cardiac and non-cardiac patients (Hoyer et al., 2008). The CAQ is an 18-item self-report inventory scored on a five-point Likert scale, anchored from 0 (never) to 4 (always), including three

dimensions. It assesses 1) fear of heart sensations and functioning, e.g. "I worry that I may be having a heart attack"; 2) the avoidance of activities believed to elicit symptoms, e.g. "I avoid exercise or other physical work"; and 3) heart-focused attention and monitoring, e.g. "I can feel my heart in my chest". A total score for heart-focused anxiety ranging from 0 to 32 was calculated and totals for each of the subscales were also calculated. Higher scores indicated greater heart-focused anxiety.

5.5.6 Somatisation

The Patient Health Questionnaire-15 (PHQ-15) (Kroenke, Spitzer, & Williams, 2002) was used as a measure of somatic symptom severity. Participants were asked to rate fifteen somatic symptoms, ten of which are the diagnostic symptoms of DSM-IV somatisation disorder, as either 0 ("not bothered"), 1 ("bothered a little"), or 2 ("bothered a lot"). These symptoms were stomach pain, back pain, pain in limbs or joints, menstrual pain (women only), headaches, chest pain, dizziness, fainting spells, pounding/racing heart, shortness of breath, pain or problems during sexual intercourse, bowel complaints (constipation or diarrhoea), dyspeptic complaints (nausea, gas, or indigestion), fatigue, and trouble sleeping. A total score was obtained by adding the scales and ranged from 0 to 30. The constructers of the scale categorise scores according to the following ranges: minimal (0-4), low (5-9), medium (10-14), and high (15-30). Although the PHQ-15 does not distinguish between medically explained and medically unexplained symptoms, high scores have been show to correlate highly with somatoform symptoms and are indicative of a somatoform disorder (Körber, Frieser, Steinbrecher, & Hiller, 2011; Kroenke et al., 2002). High internal reliability and convergent and discriminant validity have been demonstrated for the measure (Interian, Allen, Gara, Escobar, & Diaz-Martinez, 2006; Kroenke et al., 2002).

5.5.7 Panic

A single screening question was used to detect probable panic disorder to which participants answered "yes" or "no": "In the past 4 weeks, have you had an anxiety attack – suddenly feeling fear or panic?" This question has been validated by Lowe

et al. (2003) who found it can identify as many as 93% of patients with panic disorder. They also found it to be nearly six times more sensitive that medical doctors' detection of panic.

5.5.8 Heartburn, acid regurgitation, & dysphagia

Measures of heartburn (3 questions), acid regurgitation (3 questions), and dysphagia (3 questions) from the Gastro-Oesophageal Reflux Questionnaire (GRQ) (Locke, Talley, Weaver, & Zinsmeister, 1994), which are included in the Chest Pain Questionnaire (CPQ), were assessed. The GRQ is a self-report instrument that measures gastro-oesophageal symptoms during the prior year with 32 items, and has demonstrated acceptable reliability and validity (Locke, Talley, Fett, Zinsmeister, & Meltonlii, 1999). The median kappa statistic for test-retest reliability has been shown to be 0.70, and 0.62 for concurrent validity by physician interview (Locke et al., 1994). Participants were asked to rate how frequently they experience heartburn, acid regurgitation, and dysphagia on a scale of 1 to 6 using the following verbal rating descriptors: 1) none in past year, 2) less than once a month, 3) about once a month, 4) about once a week, 5) several times a week, or 6) daily. Heartburn was defined as a burning pain or discomfort behind the breast bone in the chest; acid regurgitation was defined as a bitter or sour-tasting fluid coming into the throat or mouth; and dysphagia was defined as trouble swallowing or a feeling that food sticks in your throat or chest. They were also asked to rate how bothersome these experiences were on a 4-point verbal rating scale of 1 (mild) to 4 (very severe). Participants who experienced heartburn, acid regurgitation, and dysphagia at a frequency of at least once per month were classified as likely indicating a gastro-oesophageal disorder, as categorised by Eslick and Talley (2004b).

5.5.9 Anxiety and depression

The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) is a 14-item self-report questionnaire widely used to measure clinically significant anxiety and depression in general medical patients. It was developed for patients in hospital settings, and excludes somatic symptoms of anxiety and depression to avoid possible confounding by somatic illnesses (Kendel et al., 2010). The measure

has been validated for use with patients with NCCP (Kuijpers et al., 2003). Two scales - the HADS-A and the HADS-D - measure anxiety and depression respectively using 7 items on verbal rating scales scored from 0 to 3. Participants were asked to rate how they felt during the past week, e.g. "I look forward with enjoyment to things". Each subscale has a possible range of 0 to 21.

5.5.10 Illness perceptions

The Brief Illness Perception Questionnaire (B-IPQ) (Broadbent, Petrie, Main, & Weinman, 2006) is an 8-item rapid assessment of patients' perceptions of their illness. It assesses cognitive and emotional representations of illness on 11-point scales ranging from 0-10. Each item assesses one of the following representations:

- Consequences - 'How much do your symptoms affect your life?'
- Timeline - 'How long do you think your symptoms will continue?'
- Personal control – 'How much control do you feel you have over your symptoms?'
- Treatment control - 'How much do you think any treatment can help your symptoms?'
- Identity - 'How much do you experience symptoms?'
- Illness concern - 'How concerned are you about your symptoms?'
- Illness understanding - 'How well do you feel you understand your symptoms?'
- Emotional affect - How much do your symptoms affect you emotionally, e.g. does it make you angry, scared, upset, or depression?'

The item on consequences assessed the expected effects of the chest pain; timeline evaluated how long the participant believed the chest pain would last; personal and treatment control assessed how likely the participant believed they could control their chest pain by personal and medical means; identity examined the symptoms they viewed as being part of their condition; illness concern assessed the extent of their concern about their chest pain; illness understanding examined how well they

understood their condition; and emotional affect evaluated the extent to which the chest pain impacted on the participants emotionally. Increases in scores corresponded to increases in the dimension measured. The B-IPQ is widely used across a broad range of illnesses and has demonstrated good test-retest reliability, concurrent validity, predictive validity, and discriminant validity (Broadbent et al., 2006; Donkin et al., 2006).

It was supplemented by the identity scale of the Illness Perception Questionnaire – Revised (IPQ-R) (Moss-Morris et al., 2002), which was adapted for cardiac symptoms with the aid of the Advanced Nurse Practitioner in cardiology. This identity scale consisted of a list of 12 symptoms that are typically associated with coronary heart disease, e.g. breathlessness, pain in arm, and loss of strength. Participants were asked whether they had experienced these symptoms ("yes" or "no") and whether they considered the symptom to be related to their chest discomfort ("yes" or "no"). The number of symptoms they endorsed as related to their chest pain formed the identity score. This score ascertained the number of cardiac-related symptoms that participants associated with their chest pain, and higher scores indicated higher identification with a cardiac condition.

5.5.11 Illness attributions

The B-IPQ includes an open-ended question about what respondents perceived to be the cause of their illness. Participants were prompted to state three possible factors that contributed to their chest pain. These responses were grouped into categories, for example, heredity or stress. An open-ended approach to measuring causal perceptions has been deemed to be advantageous over prescriptive responses (Broadbent et al., 2006). In addition, they were then asked to what degree they considered four conditions to contribute to their pain on global ratings from 1 (not at all) to 7 (very high degree), as employed by Dammen et al. (2006). These conditions included heart disease, a stomach/digestive disorder, a lung/breathing disorder, and psychological factors. Higher scores indicated greater endorsement of the attributions.

5.5.12 Social factors

Prior heart disease exposure was operationalised in the following manner. Participants were asked to give the number of their parents, family members, and close friends with a history of heart disease, as adapted from research by Aikens et al. (1999) (see Table 2.3 for more details).

5.5.13 Service-related factors

An open-ended question assessed whether participants had been offered any explanations for their discomfort by medical professionals. They also specifically answered ("yes" or "no" or "I do not know") to whether a medical professional had told them that they had angina. In addition, they rated their satisfaction with any explanations they had been given on a verbal rating scale ranging from 1 (not satisfied at all) to 5 (highly satisfied), and to what extent they felt they have been given consistent information on a similar scale from 1 (not at all consistent) to 5 (always consistent).

5.5.14 Demographics

The demographic information collected included details on gender, age, marital status, education, work status, medical card ownership, and insurance. Participants' marital status was categorised into 'single', 'partner' (married or cohabiting), and 'previously married' (widowed, separated, or divorced). Regarding educational level, participants who reached up to and including junior certificate level were labelled 'primary', those who had completed their leaving certificate were labelled 'secondary', and participants with a diploma, first degree, or higher degree were categorised as 'tertiary'. Employment was categorised into a binary variable for longitudinal analyses. Those considered employed included students and retired patients. Participants were asked whether they were covered by State funded

healthcare, i.e. whether they had a Medical Card. They were also asked whether they had a private medical insurance policy.[2]

5.5.15 Health service use

Previous health service use was assessed in an interview while participants waited for their EST. An interview was deemed necessary due to the complexity of the information being gathered. Participants' frequency of visitation to general practitioners, emergency departments, cardiologists and/or other specialists in the previous year was determined (see Appendix F). The type and number of any previous tests for the investigation of chest pain were recorded. In addition, details on whether different physicians or hospitals were frequented and the reasons why were sought. Hospital medical records in the index hospital were also examined to determine hospital visits in the hospital in the previous year.

[2] Medical card holders are entitled to free access to public health services and eligibility is determined by specified income threshold levels. Individuals who purchase private insurance are entitled to consultant-led care and other hospital benefits (e.g. private or semi-private room) in the acute hospital system (Nolan, 2007; Smith, 2007).

Domain	Measure	Items	Section	Q. No.
Chest pain	- Chest Pain Questionnaire (CPQ): Frequency, severity & duration	3	A	A2– A4
Illness characteristics	- Time waiting for EST	1	A	A1
	- CPQ: Duration	1		A5
Musculoskeletal pain	CPQ	2	A	A14-A15
Pain limitation	Brief Pain Inventory-Short Form (BPI-SF) Interference Scale	7	A	A16
Heart-focused anxiety	Cardiac Anxiety Questionnaire (CAQ)	18	A	A17
Somatisation	Patient Health Questionnaire-15	15	B	B1
Panic	Screening question	1	B	B1
Heart-burn	Gastro-Oesophageal Reflux Questionnaire (GRQ)	3	C	C1-C3
Acid regurgitation	GRQ	3	D	D1-D3
Dysphagia	GRQ	3	E	E1-E3
Anxiety	Hospital Anxiety and Depression Scales (HADS) –Anxiety subscale	7	F	F
Depression	HADS-Depression subscale	7	F	F
Illness perceptions	- Illness Perception Questionnaire Revised (IPQ-R) symptom list (adapted)	14	G	*NA*
	- Brief Illness Perception Questionnaire (B-IPQ)	8		
Illness attributions	- B-IPQ Open-ended question	1	G	*NA*
	- Global rating scales	4		
Service-related & social factors	- Service-related factors	4	H	H1-H4
	- Exposure to heart disease	1		H5
Demographics	Gender, age, marital status, education, work status, medical card, insurance	12	I	I1-I12

Figure 5.2 Baseline measurement tools

5.6 Follow-up measurement

A summary of the measures employed in the follow-up questionnaire is displayed in Table 5.2. The corresponding sections and question numbers are provided to aid inspection of the follow-up questionnaire contained in Appendix I. The primary outcome variables are persistent chest pain and persistent health service use.

Domain	Measure	Items	Section	Q. No.
Chest pain	CPQ: Frequency, severity & duration	3	A	A1– A3
Reassurance	Reassurance scale (Donkin et al., 2006)	5	I	I1-I5
Health service use	ED visits, GP visits, Cardiology clinic visits, other clinic visits	8	J	J1-J8
Service-related factors	- Cardiac medication	1	J	J9
	- Receipt of results	2	J	J10-J11
	- Explanation	2	J	J12-J13

Figure 5.3 Follow-up measurement tools

5.6.1 Chest pain

The baseline measurement of frequency, duration, and severity of chest pain was repeated at follow-up (see section 5.7.1). While these measures were treated as ordinal variables at baseline, they were categorised at follow-up in order to examine outcomes in logistic regression analyses. Two binary categorisations were calculated: 1) no chest pain versus any chest pain during follow-up period; and 2) chest pain at a frequency of less than once per month versus chest pain at a frequency of at least once per month during follow-up, as performed by Eslick and Talley (2004b).

5.6.2 Reassurance

The assessment of reassurance was made using a scale developed by Donkin et al. (2006) and Petrie et al. (2007). Participants were asked to rate - on an 11-point

scale ranging from 0 (not at all) to 10 (extremely) - five statements assessing reassurance levels. The statements were as follows:

1) How worried are you about your health?
2) Do you believe there is something seriously wrong with your heart?
3) Were you reassured by your exercise stress test?
4) How accurate do you think the test was for identifying heart problems?
5) Do you believe you need further testing to find the cause of your chest discomfort?

Reverse scoring was applied to items 1, 2, and 5 such that higher scores represent higher reassurance levels with scores ranging from 0 to 50. Good internal reliability has been demonstrated for the scale, with Cronbach alphas ranging from 0.80 to 0.88 (Donkin et al., 2006; Petrie et al., 2007).

5.6.3 Health service use

Participants were asked about attendance ("yes" or "no") at a hospital emergency department, their general practitioner, a cardiology clinic, and any another specialist clinic for the investigation of chest discomfort since their EST. They also indicated the number of visits to each healthcare setting or, in the case of attendance at another specialist clinic, they were asked to name the type of specialist from a list of the following options: 1) Gastroenterologist, 2) Respiratory Specialist, 3) Psychologist, 4) Alternative Therapist, or 5) Other.

There is no conclusive definition of persistent and/or unnecessary health service use (Glombiewski et al., 2010). In this study, persistent health service use was defined as unscheduled visitation to the emergency department and/or general practitioner for the investigation of chest pain. Other health service use in the follow-up period was not included, since referral for testing and clinic appointments was determined by their doctor and was generally outside of the patient's control. Participants who made only one visit to the general practitioner for the investigation of chest pain were not considered persistent health service users since

many returned to their doctor in order to receive test results. As continuing health service use is dependent upon having continuing symptoms, participants with chest pain who did or did not continue to use services for the investigation of their pain needed to be examined separately. Participants were therefore categorised into three groups labelled as follows: 1) no chest pain, 2) chest pain only, and 3) chest pain and health service use.

5.6.4 Service-related factors

In order to assess service-related factors, participants were asked if they had received the results of their EST ("yes" or "no"), and how they had received their results. They were also asked whether they had received any explanation for their symptoms. Their satisfaction with explanations received was rated on a 5-point Likert scale from 1 (not satisfied at all) to 5 (highly satisfied). Additionally, their use ("yes" or "no") of cardiac medication was re-assessed.

5.6.5 Telephone questionnaire

Additional details about health service use were obtained in a telephone interview (Appendix J). Any admissions to hospital and associated durations were examined. Details on any subsequent tests were gathered in an open-ended question and participants were specifically asked whether they had had an angiogram or another EST. Information on pending tests or clinic appointments was also obtained. If participants had attended a different hospital, the reasons for this were ascertained.

5.7 Pilot

The questionnaire was piloted with ten participants to ensure that the study presentation and measures were acceptable and feasible for patients. Following the completion of the questionnaires, participants were asked about the clarity of the instructions and questions and their comfort with them. All participants in the pilot maintained that they were satisfied with the questionnaire. Since no adjustments

were necessary, the data collected on these ten participants have been included in the overall analysis.

5.8 Ethical issues

Ethical approval for the research was obtained from the Ethics Committee at Beaumont Hospital (see Appendix K for approval documentation). All consultant cardiologists and charge nurses were informed about the study and their permission to approach their patients was obtained. In order to ensure informed consent, patients were given a written information leaflet (see Appendix B and C) which addressed the purpose of the research, the procedure involved, potential risks, confidentiality, and contact details of the researcher to deal with any queries. Patients were assured of anonymity and it was also explained that their choice to participate or not would not have any bearing on their medical care. All participants signed a consent form (Appendix D) confirming their informed consent.

The inclusion of a screening measure for depression in the questionnaire raised an ethical issue. The Ethics Committee asked that medical personnel should be informed about participants with high scores so that patient welfare could be protected. A cut-off value of >10 for the HADS-D was chosen which has been shown to exclude depression very well as demonstrated by a recent meta-analysis which calculated a specificity value of 0.92 (Brennan, Worrall-Davies, McMillan, Gilbody, & House, 2010). However, a sensitivity of 0.56 was calculated, indicating it did not correctly identify depression with a good degree of certainty. Nevertheless, it was chosen as the optimal value for informing medical doctors of a probable mood disorder in order to minimise the number of false positives. Participants were made aware that if their answers indicated that they were very distressed, relevant medical practitioners would be informed. Due to the lack of mental healthcare hospital resources, the participant's GP was deemed the most appropriate practitioner for outpatients. The participant's consultant was deemed most appropriate for inpatients. Letters (please see Appendices L and M) were sent to the relevant practitioners of participants screening positive for depression. In order

to minimise potentially inappropriate labelling and treatment, it was emphasised that the screening measure was not diagnostic for depression and that patients should be investigated further.

5.9 Data screening

Questionnaire data were entered into PASW Statistics 18 for Windows, Release 18.0 (IBM Corporation, 2009), which was used to perform all analyses. A codebook detailing the coding schemes for all items was developed to facilitate data entry. The variables and value labels were defined in PASW and text information was coded before, and not during, data entry. All variables were examined for accuracy of data entry, missing data, normality of distribution, presence of outliers, and multicollinearity. These processes will now be discussed.

5.9.1 Accuracy of data

To ensure accuracy, the original data were proofread against the PASW data file. In addition, the plausibility of the data was inspected by examining the minimum and maximum values of all variables. The means and standard deviations of continuous variables were also inspected. It was ensured that all values were within the plausible range.

5.9.2 Missing data

If there was sufficient time prior to participants' EST's, the questionnaires were inspected in order to identify any missing data and to seek responses to unanswered questions. However, this was not always feasible and therefore some missing data exists. Missing value analysis (MVA) was performed to detect missing values. Individual mean imputation was used for scales where one or two items were missing. Missing values were replaced by the average of the completed items of the scale. This method was chosen over other methods such as Multiple Imputation (MI) since it has been found to produce excellent correlation coefficients with real data, and to perform comparably as accurately as other

methods (Tabachnick & Fidell, 2007). It also has the advantage of ease of interpretability (Shrive, Stuart, Quan, & Ghali, 2006).

5.9.3 Normality of distribution

In order to assess whether variables were normally distributed, frequency histograms and Q-Q plots of each variable were visually inspected. In addition, z-scores for skew and kurtosis were calculated (see Appendix N). Skewness relates to the degree and direction of symmetry of a distribution and kurtosis relates to the peakedness of a distribution. Variables with a skew or kurtosis z-score greater than an absolute value of 3.29 were considered non-normal, as recommended by Tabachnick and Fidell (2007) and Field (2009).

Four variables, namely, pain interference, depression, attribution to a digestive cause, and perception of personal control, had skew z-scores greater than 3.29. Once square root transformations were applied to pain interference, depression, and attribution to a digestive cause, the distribution of scores became normal, as evidenced by lower z-scores and by visual inspection of histograms and Q-Q plots. Square Root Transformations reduce positively-skewed data by bringing larger scores to the centre (Field, 2009; Tabachnick & Fidell, 2007). Although z-scores for the variable perception of personal control decreased once transformation was applied, visual inspection of the histogram and Q-Q plot for the transformed variable revealed that the distribution of the scores remained non-normal. Two further variables were deemed to be non-normal upon visual inspection of the histograms and Q-Q plots, namely, attributions to respiratory and psychological causes. Square root transformations were also applied to these variables, which normalised them.

Both the original variables and their transformed counterparts were examined in subsequent analyses, but no discrepancies in terms of the statistical significance of analyses were found, and the original variables will therefore be reported in the following chapters. In addition, non-parametric analyses (i.e. logistic regression)

were primarily conducted as these are considered robust to violations of normality (Field, 2009; Tabachnick & Fidell, 2007).

5.9.4 Outliers

The procedure for the identification of outliers involved the inspection of boxplots and the comparison of means with 5% trimmed means wherein the top and bottom 5% of cases are removed. Where these figures differ significantly, extreme scores are found to exert a strong influence on the mean which can distort analyses (Tabachnick & Fidell, 2007). No outliers remained once they were checked for errors, and square root transformations of non-normal variables were performed.

5.9.5 Multicollinearity and singularity

Multicollinearity and singularity represent logical and statistical problems for an analysis. Multicollinearity occurs when variables are very highly correlated and singularity occurs when a variable is a combination of two or more of the other variables (Tabachnick & Fidell, 2007). When variables that are multicollinear or singular are included in an analysis, redundant information is included and the size of error terms is inflated, thereby weakening the analysis. In the logistic and multinomial logistic regression analyses, standard errors were inspected for inflated values, as recommended by Tabachnick and Fidell (2007). Singularity was avoided by avoiding the inclusion of both scales and their composite subscales in multivariate analyses. Further details on variable selection in relation to the consideration of multicollinearity and singularity will be provided in subsequent chapters.

5.10 Scale reliability

The reliability of the scales were assessed by calculating the Cronbach alpha (α) of each scale, the most frequently used indicator of internal consistency (see Table 5.3). A coefficient of 0.7 or above is typically deemed acceptable (Kline, 1999). As can be seen in Table 5.3, all scales satisfy this criterion with the exception of CAQ-

Attention. However, the alpha just falls short of 0.7 and all scales are therefore considered to indicate satisfactory internal consistency reliability.

Table 5.1 Cronbach's alpha (α) coefficients indicating scale reliability

Scale	N	Cronbach's alpha (α)
HADS-A	142	0.817
HADS-D	142	0.768
BPI-SF	131	0.900
CAQ	138	0.831
CAQ-Fear	138	0.826
CAQ-Avoidance	139	0.860
CAQ-Attention	139	0.652
PHQ-15	142	0.810
Reassurance	102	0.743

5.11 Statistical analysis

The following three chapters present the statistical analyses. All tests were two-tailed at a significance level of $p<0.05$.

5.11.1 Descriptive statistics

Mean values (*M*) and standard deviations (*SD*) are reported for normally distributed continuous variables, and median values (*Md*) and interquartile ranges (*IQR*) are reported for ordinal variables and continuous variables with evidence of non-normal distribution. Categorical variables are presented as proportions. Chi-squared tests (χ^2) were used to compare categorical variables between groups, and where zero was present in cells, Fischer's exact tests were employed. Mann-Whitney U-Tests (z) were used to compare continuous variables that deviated from normality. Correlations were assessed using Pearson Product-Moment correlations for normally-distributed continuous variables and Spearman rank correlations (rho) for ordinal variables or non-normally distributed continuous variables. In order to examine differences between participants and non-participants at follow-up,

logistic regression analyses were conducted. The Wilcoxon test was used for repeated-measures categorical and ordinal data. The statistical methodology for examining the outcomes of persistent pain and persistent health service use is explained in more detail in the next section.

5.11.2 Logistic regression analysis

Logistic regression is the most commonly used method for analysing binary outcome variables (Kirkwood & Sterne, 2003). It is a very flexible method in that the assumptions of linearity, normal distribution, and homoscedasticity are not needed. In addition, both continuous and categorical independent variables can be examined as predictors of the outcome (Field, 2009; Tabachnick & Fidell, 2007). The natural log of the odds of the dependent variable is calculated and maximum likelihood estimation is applied to estimate the odds of the outcome occurring. Odds ratios for each independent variable are calculated, which are measures of effect size. An odds ratio of 1 corresponds to no effect on the outcome. An odds ratio greater than 1 indicates greater odds of the outcome occurring. If the value is less than 1, the odds of the outcome occurring decreases as the predictor increases (Field, 2009).

Logistic regression analysis was chosen as the primary statistical technique due to its ability to analyse both categorical and continuous variables, its robustness to violations of normality, and its ease of interpretability (Tabachnick & Fidell, 2007). For the assessment of predictors of persistent chest pain, univariable logistic regression analyses were conducted to estimate unadjusted odds ratios and 95% confidence intervals, which demonstrated the association between baseline variables and pain at follow-up.

Univariable analyses informed the selection of variables for inclusion in multivariate logistic regression models. Variables with p values less than 0.15 at univariate level were entered into multivariate models. This is a recommended, conservative criterion for selecting and retaining variables in regression models (Bursac, Gauss, Williams, & Hosmer, 2008; Hosmer & Lemeshow, 1999). Multicollinearity reduces

the precision of estimated odds ratios in multivariate analyses (Bagley, White, & Golomb, 2001). It was assessed by examining whether exceptionally large (>2) standard errors existed (Tabachnick & Fidell, 2007). Examination of interactions in multivariate analyses was not conducted since little is known about interaction in this population group. It has been recommended that for modest samples, the consideration of interaction terms should be governed by prior knowledge (Bagley et al., 2001). In addition, formal tests for interaction lack power to detect any but the strongest interactions (Kirkwood & Sterne, 2003).

5.11.3 Multinomial logistic regression analysis

In order to examine persistent health service use for chest pain, participants were categorised into three groups, and multinomial logistic regression analyses were conducted. Multinomial logistic regression predicts the odds of an outcome with more than two categories, and employs a combination of binary logistic regression analyses (Field, 2009). The three categories of the outcome in this study were: 1) no chest pain, 2) chest pain only, and 3) chest pain and health service use. The category 'no chest pain' was used as a reference group and separate odds ratios were determined for membership of the other two categories. Univariable analyses estimated unadjusted odds ratios and 95% confidence intervals for the predictive value of baseline variables. The ability of these baseline variables to distinguish between participants with and without persistent health service use was examined. The criterion of p values less than 0.15 for the selection of variables for the multivariate models was again employed, as described in section 5.11.2.

Further details on statistical methods will be presented in the following three chapters.

Chapter 6: Prospective Cohort Study – Baseline Findings

6.1 Overview

This chapter outlines the recruitment process and presents the demographic profile of participants with NCCP at baseline and follow-up. Descriptive statistics profiling the sample recruited are reported. Chest pain and the main study variables at baseline are examined, including physical, psychological, social, and service-related variables.

6.2 Participants

A flowchart illustrating numbers of participants at each stage of recruitment is displayed in Figure 6.1. Of 712 patients assessed for eligibility, 321 satisfied the inclusion criteria. Patients were ineligible for the following reasons: previous cardiac history; no chest pain; hospital employee; aged less than 18 years; unable to communicate in English; cognitive impairment precluding competent participation; or cancellation of test. Eighty six patients were not invited to participate since they were not contactable (outpatients) or moved through the hospital system too quickly to be approached prior to testing (inpatients). Of the remaining 235 patients, 169 were recruited, which represented 53% of potential participants and a participation rate of 72% of those who were invited to participate. This sample consisted of 121 outpatients and 48 inpatients. Participation rates of 84% and 68% were achieved for inpatients and outpatients, respectively. When participants and non-participants were compared, women were equally as likely to participate as men (OR=0.75, 95% CI 0.47-1.18, p=0.213), and there was no difference in age (OR=1.01, 95% CI 0.99-1.03, p=0.323). Other factors potentially differed across participants and non-participants, but further details on non-participants were not accessible.

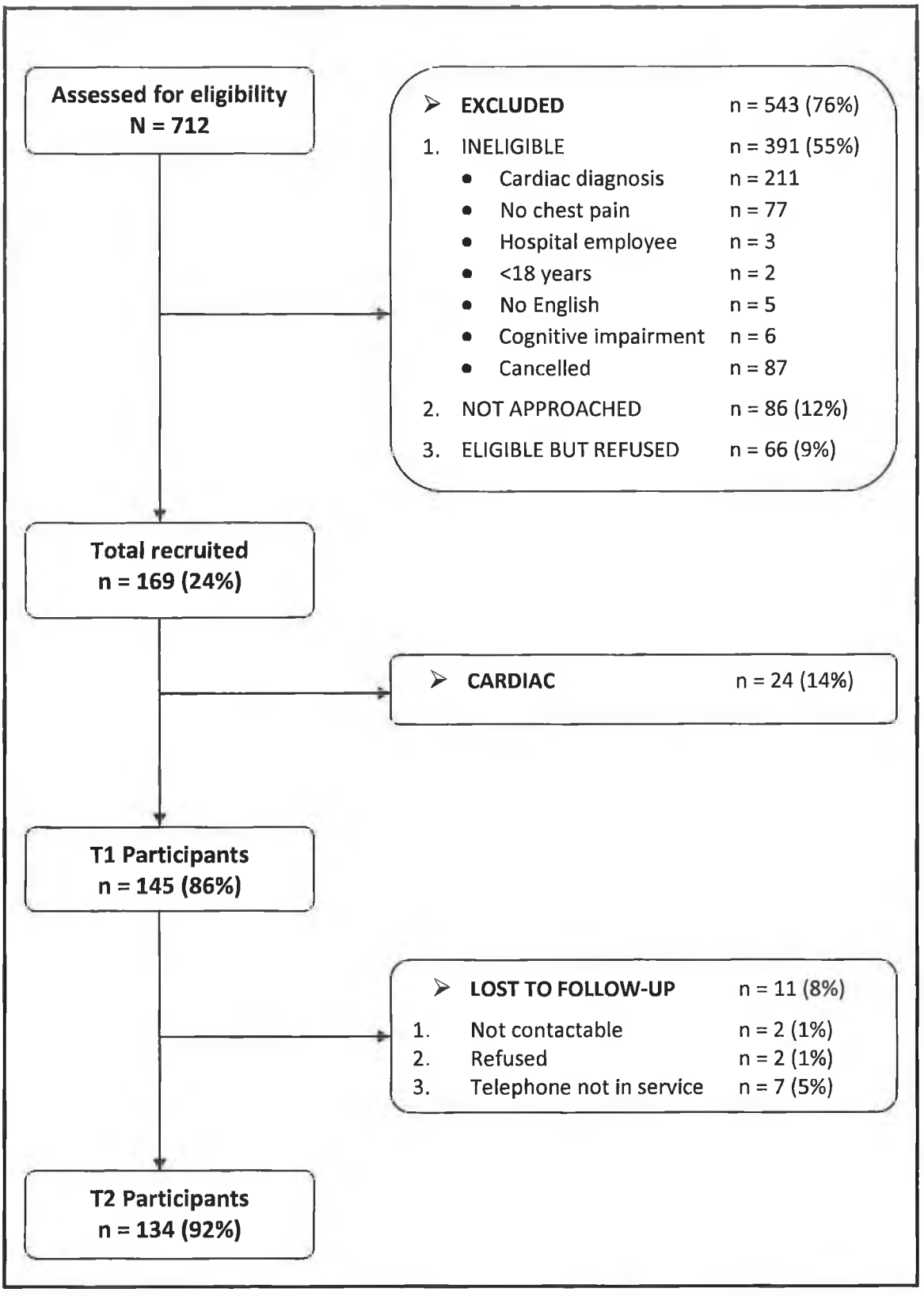


Figure 6.1 Flowchart of sample recruitment

At one-year follow-up, 145 (86%) participants had normal cardiac test results. This non-cardiac sample consisted of 108 outpatients and 37 inpatients, which represented 89% of outpatients recruited and 77% of inpatients recruited. The follow-up response rate was 92%, giving a follow-up sample of 134 participants.

6.3 Participant characteristics

6.3.1 Demographic profile

Details on the demographic profile of participants at baseline are presented in Table 6.1. At baseline, the age of participants ranged from 18 to 83 years with an average age of 51 years (standard deviation (*SD*)=13.6).

Table 6.1 Demographic profile at baseline

Demographic variables	n	Baseline Profile n=145
Age, n (%)	145	
18-44		46 (32)
45-64		69 (48)
65+		30 (21)
Gender, n (%)	145	
Male		69 (47.6)
Female		76 (52.4)
Marital Status, n (%)	133	
Single		16 (12.0)
Married/cohabiting		98 (73.7)
Widowed/separated/divorced		19 (14.3)
Education, n (%)	132	
Primary/incomplete secondary		68 (51.5)
Secondary		22 (16.7)
Third level		42 (31.8)
Employment, n (%)	131	
Employed		70 (53.4)
Unemployed		13 (9.9)
Unable to work		8 (6.1)
Retired		18 (13.7)
Student/home duties		22 (16.8)
Public health insurance, n (%)	125	57 (45.6)
<70 years	105	45 (40.2)
70+ years	14	12 (92.3)
Private health insurance, n (%)	119	49 (41.2)
<70 years	67	45 (42.9)
70+ years	13	4 (28.6)

Almost equal proportions of men and women were enrolled in the study. Nearly three quarters of the sample were married or cohabiting and the remainder were single, widowed, separated, or divorced. Just over half of the participants had not completed secondary education, while nearly a third had a third-level education. Fifty three per cent were employed. Employment and education were significantly related (χ^2=21.70, p=0.006). The proportion of participants without any medical insurance cover, i.e. neither medical card nor private health insurance, was 23%, which was the same proportion found in the Quarterly National Household Survey in 2010 (Central Statistics Office, 2011). However, as can be seen from the number of respondents to questions on public (n=125) and private (n=119) health insurance, not all respondents were comfortable providing information on their insurance status. Of those who respondents, a higher proportion than the national survey had medical cards (39% vs. 30%) and a lower proportion had private health insurance (33% vs. 47%), indicating a slightly more deprived sample than the general population.

6.3.2 Symptom profile

Details on the frequency, severity, duration, commencement, and associated interference of chest pain are provided in Table 6.2, according to patient type (outpatient/inpatient). There was a wide variety in chest pain frequency reported. One in ten (11%) had only experienced chest pain once, whereas one quarter of participants reported chest pain several times a week and half (49%) experienced episodes at least weekly. Frequency ratings differed significantly between outpatients and inpatients (χ^2=11.54, p=0.042). It was the first experience of chest pain for one quarter of inpatients compared to just 6% of outpatients. Nevertheless, almost half (46%) of inpatients reported symptoms at least weekly, which was close to the proportion of outpatients with comparative frequency (53%).

Just over half of participants (52%) described their pain as at moderate intensity, roughly equal proportions rated it mild and severe, and relatively few (4%) rated it very severe. Severity ratings were not different between inpatients and outpatients

(χ^2=5.33, p=0.149), but there was a non-significant tendency for inpatients to rate the intensity higher. Chest pain duration ranged from less than a minute to more than one hour. Almost two thirds of participants (63%) stated it generally lasted no more than fifteen minutes. Nearly one fifth (18%) claimed it usually lasted more than one hour. Differences in duration across patient type were not statistically significant (χ^2=4.35, p=0.500).

About one half of participants had developed chest pain within the preceding year and almost 10% had been experiencing symptoms for ten years or more. The profile differed significantly by patient type (inpatients versus outpatients) (χ^2=58.23, p<0.001). Fifty seven per cent of inpatients had developed symptoms within the last three months compared to just 3% of outpatients. Chest pain commenced less than two years ago for the vast majority of inpatients (89%) compared to just over half (55%) of outpatients. Interference scores ranged from 0 to 70 out of a possible 70 but the majority reported mild interference levels. The median (*Md*) score was 21 with an interquartile range (IQR) of 9 to 32. Inpatients indicated slightly higher scores (*Md*=24.5 vs. *Md*=18.0), yet this difference was not statistically significant (z=1.70, p=0.090).

Table 6.2 Symptom profile at baseline according to patient type

Symptom variables	n	Total Sample	Outpatients (74%)	Inpatients (26%)	Statistic
Frequency, n (%)	134				χ^2=11.54*
Once		15 (11.2)	6 (6.1)	9 (25.7)	
< once a month		20 (14.9)	16 (16.2)	4 (11.4)	
About once a month		31 (23.1)	25 (25.3)	6 (17.1)	
About once a week		24 (16.2)	20 (20.2)	4 (11.4)	
Several times a week		34 (25.4)	24 (24.2)	10 (28.6)	
Dally		10 (7.5)	8 (8.1)	2 (5.7)	
Severity, n (%)	137				χ^2=5.33
Mild		29 (21.2)	23 (22.8)	6 (16.7)	
Moderate		71 (51.8)	56 (55.4)	15 (41.7)	
Severe		32 (23.4)	19 (18.8)	13 (36.1)	
Very severe		5 (3.6)	3 (3.0)	2 (5.6)	
Duration, n (%)	136				χ^2=4.35
< 1 minute		19 (14.0)	15 (14.9)	4 (11.4)	
1-5 minutes		41 (30.1)	33 (32.7)	8 (22.9)	
5-15 minutes		26 (19.1)	16 (15.8)	10 (28.6)	
15-30 minutes		17 (12.5)	14 (13.9)	3 (8.6)	
30-60 minutes		8 (5.9)	6 (5.9)	2 (5.7)	
More than 1 hour		25 (18.4)	17 (16.8)	8 (22.9)	
Commencement, n (%)	138				χ^2=58.23***
Last 3 months		23 (16.7)	3 (2.9)	20 (57.1)	
Last 6 months		22 (15.9)	17 (16.5)	5 (14.3)	
6 months – 1 year		20 (14.5)	18 (17.5)	2 (5.7)	
1-2 years		22 (15.9)	18 (17.5)	4 (11.4)	
2-5 years		27 (19.6)	24 (23.3)	3 (8.6)	
5-10 years		11 (8.0)	11 (10.7)	0	
10-20 years		9 (6.5)	8 (7.8)	1 (2.9)	
> 20 years		4 (2.9)	4 (3.9)	0	
Interference	131				
(median [IQR])		21.0 [9.0-32.0]	18.0 [8.0-30.0]	24.5 [10.0-35.5]	z=1.70

*p<0.05, ***p<0.001

6.3.3 Physical factors

Physical symptoms at baseline are summarised in Table 6.3. The proportion of participants with heartburn, acid regurgitation, and dysphagia at frequencies of at least once per month are presented. One third of participants reported heartburn, and just over one quarter reported acid regurgitation with a frequency of at least once per month in the previous year. Dysphagia, which was defined as difficulty in

swallowing, occurred in 12% with a frequency of at least once a month. In addition, over half (57%) described pain that could be musculoskeletal in origin (pain worse on movement). Two fifths (41%) reported one or two movements that precipitated chest pain and the remaining 16% reported three or more movements that induced pain.

Table 6.3 Descriptive statistics for physical variables at baseline

Physical variables	n	Total Sample
Heartburn, n (%)	133	44 (33.1)
Acid regurgitation, n (%)	131	34 (26.0)
Dysphagia, n (%)	127	15 (11.8)
Musculoskeletal Pain, n (%)	134	76 (56.7)

6.3.4 Emotional variables

Psychological variables have been categorised into 'emotional' and 'cognitive' variables. The following section presents data on emotional variables measured at baseline. This includes measures of anxiety, depression, heart-focused anxiety, somatisation, and panic, as displayed in Table 6.4. Proportions are reported for categorical variables; means and standard deviations are presented for normally distributed continuous variables; and medians and interquartile ranges are displayed for interval and non-normal continuous variables.

Table 6.4 Descriptive statistics for emotional variables at baseline

Emotional variables	n	Range	Mean (Standard Deviation) / Median (Interquartile Range)
Anxiety			
HADS-A, *M* (*SD*)	142	0-18	7.8 (4.3)
Depression			
HADS-D, *Md* [*IQR*]	142	0-16	4.0 [2.0-7.0]
Heart-focused anxiety			
CAQ, *M* (SD)	138	4-54	28.3 (11.5)
-CAQ-Fear	138	0-30	15.1 (6.7)
-CAQ-Avoidance	139	0-20	6.8 (4.9)
-CAQ-Attention	139	0-20	6.3 (3.7)
Somatision			
PHQ, *M* (*SD*)	142	0-23	9.9 (5.4)
Panic			
Screening question, n (%)	133	1=yes	32 (24.1)

6.3.4.1 Anxiety and depression

High levels of anxiety as measured by the HADS-A were found. A mean score of 7.8 was observed. Lower levels of depression were found in the sample, with a median score of 4.0 on the HADS-D.

6.3.4.2 Heart-focused anxiety

Overall levels of heart-focused anxiety measured by the Cardiac Anxiety Questionnaire were fairly high at baseline (*M*=28.3, *SD*=11.5), with three quarters of participants scoring above 20 out of a possible 72. Out of the three subscales, fear, had the highest scores (*M*=15.1, *SD*=6.7) followed by avoidance of activities (*M*=6.8, *SD*=4.9) and heart-focused attention (*M*=6.3, *SD*=3.7).

6.3.4.3 Somatisation

The mean of somatic symptom severity at baseline was 9.89 (*SD*=5.4), which just falls within the medium range according to the constructers of the scale. Minimal levels of somatic symptom severity were displayed by 17% of participants and low

levels were reported by a further 36%. Just under half fell within the medium (25%) and high (23%) categories.

6.3.4.4 Panic

Almost one quarter (24%) of participants indicated they had had a panic attack in the last four weeks, thus indicating a high likelihood of panic disorder.

6.3.4.5 Correlations between emotional variables

Relationships between the emotional variables were examined using Pearson Product-Moment correlations. As can be seen in Table 6.5, all emotional variables were significantly correlated with one another ($p<0.05$), with the exception of the correlation between panic and the CAQ subscale avoidance. According to Cohen's (1988) guidelines for assessing the strength of correlations, most correlations are medium (r=.30-.40) or large (r=.50-1.0). High correlations between variables in multivariate models can cause problems of multicollinearity, and this was considered when choosing variables for inclusion in statistical models.

Table 6.5 Pearson Product-Moment correlations between emotional variables

Variables	1.	2.	3.	4.	5.	6.	7.	8.
1. HADS-A	-	.582***	.533***	.473***	.319***	.376***	.509***	.524***
2. HADS-D		-	.488***	.333***	.483***	.261**	.526***	.348***
3. CAQ			-	.826***	.709***	.668***	.449***	.281**
4. CAQ-Fear				-	.301***	.353***	.389***	.271**
5. CAQ-Avoidance					-	.336***	.269**	.135
6. CAQ-Attention						-	.304***	.206*
7. PHQ							-	.199*
8. Panic								-

*$p<0.05$, **$p<0.01$, ***$p<0.001$

6.3.5 Cognitive variables

6.3.5.1 Illness perceptions

Illness perceptions were examined by the B-IPQ, the results of which are displayed in Table 6.6. Participants generally perceived low levels of consequences to their illness (*Md*= 3.0, *IQR* 2.0-5.0), with three quarters of participants rating at or below the midpoint of the scale. A wide spread of perceived timeline was observed; approximately half of participants indicated their illness was more chronic, while the other half indicated it was more acute (*Md*=4.0, *IQR* 2.0-7.0). Most participants did not feel they had personal control over their symptoms (*Md*=2.0, *IQR* 0.0-5.0), but they assigned a greater amount of control to medical treatment (*Md*=7.0, *IQR* 5.0-9.0), indicating a perception that medical treatment could help to alleviate their chest pain. The majority of participants were concerned about their symptoms (*Md*=6.0, *IQR* 4.0-9.0), while one quarter indicated they were not so concerned. A lack of understanding of symptoms was also common (*Md*=4.0, *IQR* 2.0-6.3). The emotional impact of chest pain was diverse amongst participants (*Md*=5.0, *IQR* 3.0-7.4), with approximately equal proportions indicating a strong and weak emotional impact. Participants were also asked to indicate whether they experienced 14 symptoms that can be related to cardiac conditions including 'breathlessness', 'pain in arm', and 'loss of strength, and whether these symptoms were related to their chest pain. This was the adapted identity scale of the IPQ-R. A median of 2.0 (*IQR* 0.0-4.0) was reported, indicating that participants generally identified with a low number of cardiac-related symptoms. When asked to rate "how much do you experience symptoms?" on the identity scale of the B-IPQ, a median of 4.0 (IQR 3.0-6.0) was found, suggesting that participants may identify more with a non-cardiac condition.

Table 6.6 Descriptive statistics for cognitive variables at baseline

Interpretation variables	n	Range	Median [*IQR*]
Illness perceptions			
B-IPQ			
-Consequences	135	0-10	3.0 [2.0-5.0]
-Timeline	122	0-10	4.0 [2.0-7.0]
-Personal control	132	0-10	2.0 [0.0-5.0]
-Treatment control	119	0-10	7.0 [5.0-9.0]
-Identity	125	0-10	4.0 [3.0-6.0]
-Illness concern	137	0-10	6.0 [4.0-9.0]
-Illness understanding	138	0-10	4.0 [2.0-6.3]
-Emotional affect	136	0-10	5.0 [3.0-7.4]
IPQ-R Identity Score	128	0-11	2.0 [0.0-4.0]
Illness attributions			
-Cardiac	122	1-7	3.0 [2.0-5.0]
-Digestive	114	1-7	2.0 [1.0-5.0]
-Respiratory	114	1-7	2.0 [1.0-5.0]
-Psychological	116	1-7	3.0 [1.0-5.0]

6.3.5.2 Illness attributions

Attributions of symptoms to a cardiac, digestive, respiratory, or psychological cause were assessed (see Table 6.6). The median attribution to a cardiac cause was 3 out of a possible 7 (*IQR* 2.0-5.0). Approximately one fifth of participants (22%) reported they believed their symptoms were definitely not related to heart disease and a larger proportion of 29% rated their attribution above the midpoint of the scale, thus indicating greater endorsement of a cardiac attribution. Attributions to a psychological cause were similar (*Md*=3.0, *IQR* 1.0-5.0). Lower attributions to both digestive (*Md*=2.0, *IQR* 1.0-4.0) and respiratory causes (*Md*=2.0, *IQR* 1.0-5.0) were observed.

Figure 6.2 displays illness attributions as determined by an open-ended assessment of cause. While only 8% attributed the cause of their chest pain directly to the heart, 12% named a family history of heart problems as a contributor and many named risk factors for heart disease. Under the heading of lifestyle, which was blamed as the cause of symptoms by 39%, smoking, alcohol, bad diet, and exercise

were included. Stress was cited by nearly one third (31%) as the cause. Almost one quarter (23%) attributed their chest pain to non-cardiac medical causes including asthma, pneumonia, acid, and indigestion. Five participants cited high cholesterol and/or high blood pressure, which are other risk factors for heart disease. Five per cent believed symptoms were the consequence of medication side effects and 4% blamed getting older. Just three female participants (2%) clamed symptoms could be attributed to the menopause.

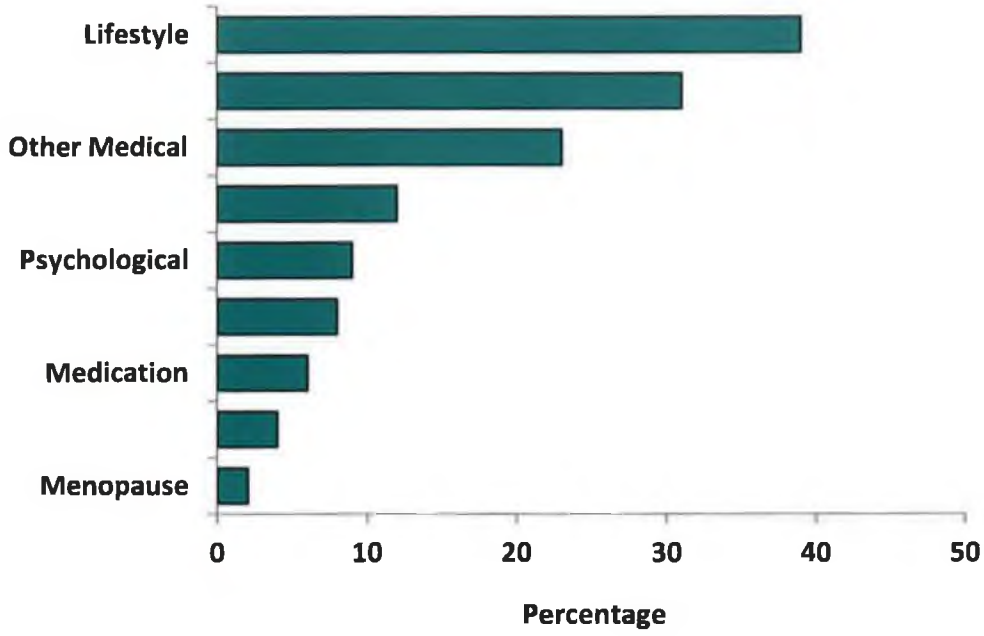


Figure 6.2 Profile of chest pain attributions

6.3.5.3 Correlations between illness perceptions scores

Associations between illness perceptions were assessed using Spearman rank order correlations, which are designed for use with ordinal or non-normally distributed variables. These correlations are presented in Table 6.7. Greater perceived consequences was significantly correlated with greater identity (rho=0.55, $p<0.001$), more illness concern (rho=0.59, $p<0.001$), and elevated emotional affect (rho=0.60, $p<0.001$). Illness concern was also significantly correlated with emotional affect (rho=0.64, $p<0.001$), and higher ratings of these dimensions were both significantly associated with greater perceived identity ($p<0.001$). The identity score

of the IPQ-R did not correlate with any of the perceptions measured by the B-IPQ, except for emotional affect (rho=-0.18, $p<0.1$). This may be due to reasons highlighted earlier (See section 6.3.5.1).

Table 6.7 Spearman (rho) correlations between illness perceptions scores

Variable	1.	2.	3.	4.	5.	6.	7.	8.	9.
1. Consequences	-	.406***	-.073	.216*	.549***	.588***	.047	.602***	-.084
2. Timeline		-	-.167	.079	.497***	.394***	-.052	.366***	-.009
3. Personal control			-	.255**	.011	-.054	.305***	-.062	.088
4. Treatment control				-	.257**	.440***	.244**	.198*	-.174
5. Identity					-	.599***	-.053	.516***	.099
6. Illness concern						-	.045	.643***	-.088
7. Illness understanding							-	-.060	-.125
8. Emotional affect								-	-.181*
9. Identity score									-

*$p<0.05$, **$p<0.01$, ***$p<0.001$

6.3.6 Social & service-related factors

The social and service-related variables examined in this study are summarised in Table 6.8. Exposure to heart disease was explored by examining the history of heart disease of parents, other family members, and friends. Just over half of participants had at least one parent with heart disease and 15% had both. About three fifths had other family members with a heart condition and one fifth claimed they had close friends with heart disease. Service-related factors included time waiting for tests, previous investigations, and pre-emptive explanations of angina. Waiting times for exercise stress tests ranged from 1 to 245 days and outpatients waited a median of 123 days (*IQR* 117-128). Inpatients were generally tested within one day. One quarter of participants had a previous normal exercise stress test and 14% had a previous normal angiogram. Only one inpatient had an angiogram prior to admission, compared to 18% of outpatients. Nine per cent of all participants claimed their doctor had already given them an explanation of angina for their

symptoms, despite a lack of clinical findings, and a further 6% were unsure. When asked to rate their satisfaction levels with the information they had been provided by medical practitioners, the median response was 'somewhat satisfied'. One fifth of participants were not satisfied at all and nearly one half were either mostly or highly satisfied. Similar responses were obtained when participants were asked to rate the level of consistency of the information they had received about their chest pain. The median rating was 'somewhat consistent', with 15% claiming the information was not consistent at all, and 46% reporting the information to be mostly or highly consistent.

Table 6.8 Descriptive statistics for social & service-related variables at baseline

Social & service-related variables	n	Total
Waiting time for EST (days)		
(median [IQR])	135	118.0 [1.0-126.0]
Previous cardiac tests		
Previous EST (%)	118	30 (25.4)
Previous angiogram (%)	118	17 (14.4)
Explanation of angina provided	136	12 (8.8)
Family History		
One parent	105	66 (53.7)
Two parents	105	18 (14.6)
Others	73	73 (61.3)
Friends	86	21 (21.9)
Satisfaction with information, Md [IQR]	118	3.0 [2.0-4.0]
Consistency of information, Md [IQR]	110	3.0 [2.0-4.0]

6.4 Summary

This chapter reported on participants' profiles in relation to demographics and chest pain symptoms, as well as examining descriptive statistics for the main study variables at baseline. The results can be summarised as follows:

- Participants had an average age of 51 years, nearly one third had completed third-level education, and half were employed.
- Participants waited on average approximately four months for their exercise stress test. One quarter had a previous normal exercise stress test and 14% had a previous normal angiogram.
- A strong family history of heart disease was observed; one half of participants had at least one parent with a heart condition.
- Chest pain occurred at least once a week for half of participants.
- Approximately half rated their chest pain at moderate intensity and over one quarter reported severe or very severe pain.
- Chest pain had commenced more recently in inpatients.
- Symptoms of heartburn and acid regurgitation were common (33% and 26% respectively), and over half (57%) indicated musculoskeletal-like pain.
- High levels of psychological distress were observed. Almost one quarter screened positive for panic disorder, and high levels of heart-focused anxiety and somatic symptom severity were found.
- Both positive and negative illness perceptions were indicated. Participants perceived low levels of consequences to their illness and believed treatment could help their symptoms, yet they also reported low levels of perceived personal control, high levels of concern, and a lack of understanding of their condition.
- Attribution of chest pain to a cardiac cause was observed in 29% of participants and many cited risk factors for heart disease as the cause of symptoms.

The next chapter examines the longitudinal findings of the study, and particularly focuses on the primary outcome of persistent chest pain. The relationship between baseline variables presented in this chapter and persistent pain at one-year follow-up are explored.

Chapter 7: Prospective Cohort Study – Longitudinal Findings

7.1 Introduction

This chapter begins by assessing the potential for participation bias in the follow-up sample. Next, the proportion of participants who received their test results and received an explanation for their chest pain is examined. The outcome variable of chest pain at follow-up is then examined. This is the primary focus of this chapter. Predictors of persistent pain are analysed in univariate and multivariate logistic regression models and the results are presented.

7.2 Follow-up participation

The profile of participants and non-participants at one-year follow-up across all variables was compared, and is presented in Table 7.1. Binary logistic regression analyses were computed except for the variables *prior angiogram* and *dysphagia*, which were analysed using two-sided Fisher's exact tests due to zero cells. The follow-up profile was similar for all demographic indices, chest pain measures, physical symptoms, and social and service-related factors. However, participants differed on a number of emotional and cognitive variables. Participants tended to have lower scores on the HADS-D, indicating lower levels of depression (OR=0.42, 95% CI 0.19-0.93, p=0.034). Participants also had lower levels of heart-focused anxiety (OR=0.93, 95% CI 0.87-0.99, p=0.019) and somatic symptom severity (OR=0.85, 95% CI 0.76-0.96, p=0.010). Trends towards lower levels of panic and anxiety were also observed. The results indicate a possible participation bias towards lower levels of psychological morbidity. When illness perceptions were examined, participants appeared to perceive lower personal control (OR=0.81, 95% CI 0.67-0.98, p=0.012), had less illness concern (OR=0.74, 95% CI 0.56-0.97, p=0.032), and less understanding of their condition (OR=0.78, 95% CI 0.64-0.95, p=0.016).

Table 7.1 Profile of participants and non-participants at follow-up

Variables	n	Respondents (n=134)	Non-respondents (n=11)	OR	95% CI	p
Age, *M (SD)*	145	51.68 (13.45)	44.73 (14.25)	1.04	0.99-1.09	.107
Female, n (%)	145	76 (52.4%)	70 (52.2%)	0.91	0.27-3.13	.883
Marital Status, n (%)	133					.694
Single		16 (12.0%)	14 (11.4%)	1	-	-
Married/Cohabiting		98 (73.7%)	91 (74.0%)	1.86	0.35-0.86	.467
Separated/Widowed		19 (14.3%)	18 (14.6%)	2.57	0.21-31.33	.459
Education, n (%)	132					
Primary		68 (51.5%)	65 (53.3%)	1	-	-
Secondary		22 (16.7%)	20 (16.4%)	0.46	0.07-2.96	.415
Third level		42 (31.8%)	37 (30.3%)	0.34	0.08-1.51	.157
Employed, n (%)	132	65 (53.3%)	5 (50.0%)	1.13	0.33-3.88	.846
Public insurance, n (%)	125	57 (45.6%)	51 (44.0%)	0.39	0.09-1.65	.201
Private insurance, n (%)	119	49 (41.2%)	47 (42.0%)	1.81	0.34-9.72	.490
CP Frequency, *Md [IQR]*	134	5.0 [3.0-6.0]	5.0 [4.0-6.0]	0.87	.56-1.33	.511
CP Severity, *Md [IQR]*	137	2.0 [2.0-3.0]	2.0 [2.0-2.0]	1.01	0.45-2.26	.986
CP Duration, *Md [IQR]*	136	3.0 [2.0-5.0]	3.0 [2.0-4.0]	1.05	0.72-1.52	.801
CP Commencement, *Md [IQR]*	138	4.0 [2.0-5.0]	3.0 [2.0-5.0]	1.08	0.78-1.49	.658
CP Interference, *Md [IQR]*	131	19.0 [8.3-31.8]	28.0 [19.0-41.0]	0.98	0.94-1.01	.162
Heartburn, n (%)	133	41 (33.6%)	3 (27.3%)	1.35	0.34-5.36	.670
Acid, n (%)	131	32 (26.7%)	2 (18.2%)	1.64	0.34-7.98	.542
Dysphagia$^{\Phi}$, n (%)	127	15 (12.9%)	0	-	-	.359
Musculoskeletal pain, n (%)	134	9 (81.8%)	67 (54.5%)	0.27	0.06-1.28	.099
HADS-A, *M (SD)*	142	7.64 (4.18)	10.09 (5.24)	0.88	0.76-1.01	.075
HADS-D, *Md [IQR]*	**142**	**4.0 [2.0-6.0]**	**7.0 [3.0-9.0]**	**0.83**	**0.71-0.98**	**.025***
CAQ, *M (SD)*	**138**	**27.61 (11.45)**	**36.45 (9.45)**	**0.93**	**0.87-0.99**	**.019***
CAQ-Fear	**138**	**14.71 (6.54)**	**19.36 (7.75)**	**0.90**	**0.81-0.99**	**.032***
CAQ-Avoidance	139	6.59 (4.82)	9.55 (5.48)	0.89	0.79-1.01	.062
CAQ-Attention	139	6.22 (3.78)	7.55 (3.01)	0.91	0.78-1.07	.259
PHQ-15, *M (SD)*	**142**	**9.53 (5.29)**	**14.18 (5.15)**	**0.85**	**0.76-0.96**	**.010***
Panic, n (%)	133	27 (22.0%)	5 (50.0%)	0.28	0.08-1.04	.058
IPQ, *Md [IQR]*						
IPQ Consequences	135	3.0 [2.0-5.0]	5.0 [3.0-8.0]	0.81	0.66-1.00	.053
IPQ Timeline	122	4.0 [2.0-7.0]	5.0 [2.0-5.0]	1.02	0.85-1.23	.828
IPQ Personal Control	**132**	**2.0 [0.0-5.0]**	**4.0 [3.0-8.0]**	**0.81**	**0.67-0.98**	**.012***
IPQ Treatment Control	119	6.5 [4.3-9.0]	9.0 [6.0-10.0]	0.76	0.58-1.01	.054
IPQ Identity	125	4.0 [3.0-6.0]	5.0 [3.0-7.0]	0.87	0.66-1.13	.381
IPQ Illness concern	**137**	**6.0 [4.0-8.0]**	**10.0 [5.0-10.0]**	**0.74**	**0.56-0.97**	**.032***
IPQ Understanding	**138**	**3.0 [2.0-6.0]**	**6.0 [3.0-10.0]**	**0.78**	**0.64-0.95**	**.016***
IPQ Emotional affect	136	5.0 [3.0-7.0]	7.0 [3.0-10.0]	0.84	0.67-1.04	.105
IPQ Identity Score, *Md [IQR]*	128	2.0 [0.0-4.0]	0.0 [0.0-0.0]	0.99	0.81-1.21	.898
Cardiac Attribution, *Md [IQR]*	122	3.0 [2.0-5.0]	4.5 [1.8-5.3]	0.89	0.66-1.21	.455
Digestive Attribution, *Md [IQR]*	114	1.5 [1.0-4.0]	2.5 [1.0-3.5]	1.02	0.72-1.43	.810
Respiratory Attribution, *Md [IQR]*	114	2.0 [1.0-4.8]	4.5 [1.0-6.0]	0.78	0.58-1.05	.098
Psychological Attribution, *Md [IQR]*	116	2.0 [1.0-5.0]	5.0 [2.5-6.3]	0.74	0.55-1.00	.053
Inpatient, n (%)	145	33 (24.6%)	4 (36.4%)	0.57	0.16-2.08	.396
Previous EST, n (%)	118	28 (25.7%)	2 (22.2%)	1.21	0.24-6.17	.819
Previous Angiogram$^{\Phi}$, n (%)	118	17 (15.6%)	0	-	-	.354
Explanation of Angina, n (%)	136	11 (8.8%)	1 (9.1%)	0.97	0.11-8.26	.974
Family History (parent), n (%)	105	59 (62.8%)	7 (63.6%)	0.96	0.26-3.53	.955
Satisfaction with info, *Md [IQR]*	118	3.0 [2.0-4.0]	3.0 [2.0-4.0]	1.08	0.67-1.75	.750
Consistency of info, *Md [IQR]*	110	3.0 [2.0-4.0]	3.5 [3.0-4.0]	0.75	0.41-1.36	.341

Φ Fischer's exact test used

Due to the small number of non-respondents, it is difficult to ascertain whether these differences and trends would survive multivariate adjustment, and they may be negligible. However, these differences should be kept in mind when interpreting subsequent analyses.

7.3 Results and explanation

At the one-year follow-up, the majority of participants had been informed about the normal result of their exercise stress test. However, 40 participants (30%) reported that they had not been informed about their results. All participants were also asked whether they received an explanation for their chest pain. Two thirds (66%) felt they had not been offered a causal explanation (see Figure 7.1). For those who had, physical explanations included gastrointestinal (GI) causes (6%), muscular problems (3%), and respiratory disorders (2%). An explanation of stress was offered to 5% and a psychological explanation to 4%. A further 3% were informed that the cause was likely to be an interaction between physical and psychological factors.

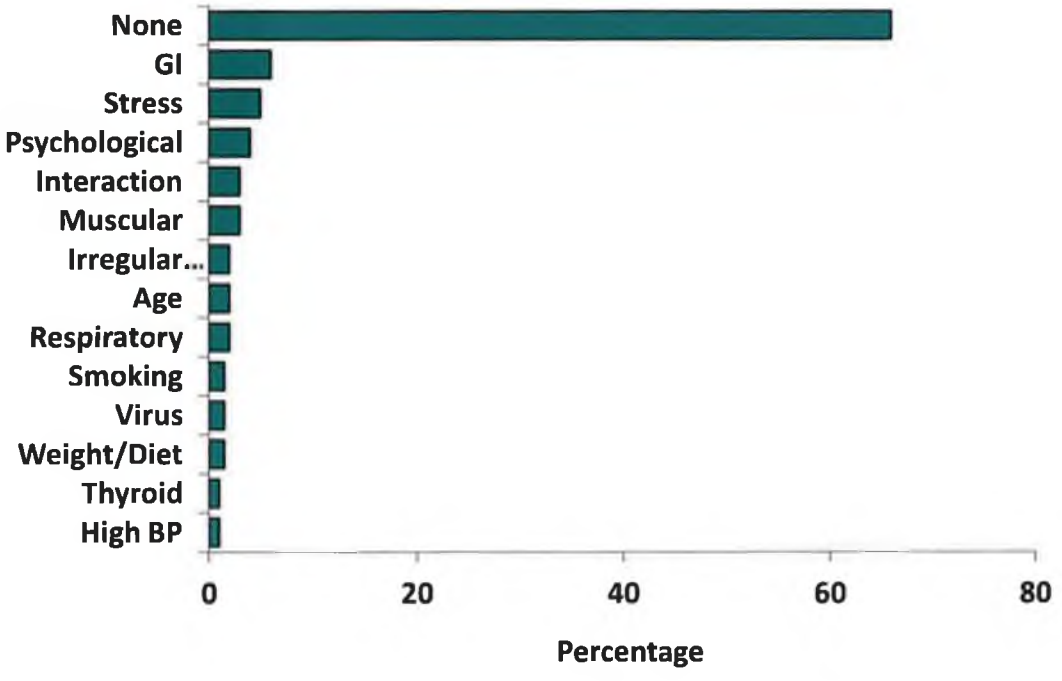


Figure 7.1 Explanation for non-cardiac chest pain

7.4 Chest pain at follow-up

Chest pain at one-year follow-up is summarised in Table 7.2. Improvement in the frequency and severity of chest pain was examined by the Wilcoxon test. Although the frequency of symptoms reduced significantly (z= -5.638, p<0.001), over two thirds of participants (69%) continued to experience chest pain and nearly one half (46%) reported it at a frequency of at least once a month. Almost one third (31%) had no further symptoms of chest pain over the follow-up period, however. Severity ratings reduced significantly (z= -6.466, p<0.001), yet approximately one in seven of those who continued to experience chest pain rated their pain as severe.

Table 7.2 Chest pain at baseline and follow-up

Symptom variables	Baseline n	Baseline n (%)	Follow-up n	Follow-up n (%)	Statistic
Frequency	n=134		n=134	n=134	z = -5.638***
None		0		42 (31.3%)	
Once		15 (11.2%)		2 (1.5%)	
Less than once a month		20 (14.9%)		29 (21.6%)	
About once a month		31 (23.1%)		21 (15.7%)	
About once a week		24 (16.2%)		16 (11.9%)	
Several times a week		34 (25.4%)		15 (11.2%)	
Daily		10 (7.5%)		9 (6.7%)	
Severity	n=137		n=134		z = -6.466***
None		0		42 (31.3%)	
Mild		29 (21.2%)		39 (29.1%)	
Moderate		71 (51.8%)		37 (27.6%)	
Severe		32 (23.4%)		14 (10.4%)	
Very severe		5 (3.65)		2 (1.5%)	

** p < .01 *** p < .001

In order to examine persistent chest pain, symptom frequency at follow-up was dichotomised into two categories, as conducted by the constructers of the Chest Pain Questionnaire (CPQ) (Eslick & Talley, 2008b). Chest pain at a frequency of less than once per month was compared with chest pain at a frequency of at least once per month. There were 73 (54.5%) and 61 (45.5%) participants in these categories,

respectively. The predictive value of baseline variables in determining persistent chest pain was assessed using univariable and multivariate logistic regression analyses, which estimated odds ratios and 95% confidence intervals for their associations. Demographic, physical, emotional, cognitive, social, and service-related variables were all examined.

7.5 Predictors of chest pain at follow-up

7.5.1 Demographic variables

Univariable logistic regression analyses were used to estimate odds ratios and 95% confidence intervals for the association between demographic variables and persistent NCCP. The results are presented in Table 7.3.

Table 7.3 Logistic regression analyses of demographic variables as predictors of persistent chest pain

Demographic variables	Improved CP n=73 (54.5%)	Persistent CP n=61 (45.5%)	OR	95% CI	*p*
Age, *M* (*SD*)	53.3 (13.3)	49.8 (13.4)	0.98	0.96-1.01	.127
Female, n (%)	38 (52.1%)	32 (52.5%)	1.02	0.52-2.01	.963
Marital Status, n (%)					
Single	6 (9.2%)	8 (13.8%)	1	-	-
Married/cohabiting	47 (72.3%)	44 (75.9%)	0.70	0.23-2.19	.542
Widowed/separated/ divorced	12 (18.5%)	6 (10.3%)	0.38	0.09-1.59	.183
Education, n (%)					
Primary/incomplete secondary	33 (50.8%)	32 (56.1%)	1	-	-
Secondary	13 (20.0%)	7 (12.3%)	0.56	0.20-1.57	.267
Third level	19 (29.2%)	18 (31.6%)	0.98	0.44-2.19	.955
Employed, n (%)	**52 (61.9%)**	**32 (43.9%)**	**0.28**	**0.13-0.64**	**.002****
Medical card, n (%)	25 (39.1%)	26 (50.0%)	1.56	0.74-3.27	.238
Private health insurance, n (%)	28 (45.2%)	19 (38.0%)	0.74	0.35-1.59	.446
Inpatient	19 (57.6%)	14 (42.4%)	0.85	0.38-1.87	.681

* $p<0.05$

The only demographic variable that was significantly associated with persistent NCCP was employment status. Participants who were employed, including

participants who were retired or full time students, had a lower odds of having persistent pain, compared to participants who were unemployed (OR=0.28, 95% CI 0.13-0.64, p=0.002). Employment appears to have been a protective factor against persistent pain and will therefore be adjusted for in multivariate analyses. There also appears to be a trend that participants with persistent pain tend to be slightly younger, but this difference was not statistically significant. Differences between participants with improved and continued chest pain were not found for other demographic indices including gender, marital status, and education status. In addition, chest pain at follow up did not differ by medical card, private health insurance status, or by patient type (inpatient/outpatient). Patient type will be included in multivariate analyses, however, as pain ratings at baseline differed by patient type (see Table 6.2).

7.5.2 Chest pain variables

The relationship between the measures of chest pain at baseline and pain at follow-up were examined (see Table 7.4). Higher chest pain frequency at baseline was related to a higher odds of persistent pain (OR=1.43, 95% CI 1.19-2.00, p=0.001). In addition, higher levels of pain interference at baseline were associated with a higher odds of persistent pain (OR=1.23, 95% CI 1.02-1.48, p=0.032). Severity ratings, pain duration, and time since onset of symptoms were not related to the outcome of persistent pain.

Table 7.4 Logistic regression analyses of chest pain variables as predictors of persistent chest pain

Chest pain variables	Improved CP	Persistent CP	OR	95% CI	*p*
Frequency, *Md* [*IQR*]	**4.0 [3.0-5.0]**	**5.0 [4.0-6.0]**	**1.54**	**1.19-2.00**	**.001****
Severity, *Md* [*IQR*]	2.0 [2.0-2.0]	2.0 [2.0-3.0]	1.19	0.76-1.87	.441
Duration, *Md* [*IQR*]	3.0 [2.0-5.0]	3.0 [2.0-4.0]	0.89	0.72-1.09	.252
Commencement, *Md* [*IQR*]	3.0 [2.0-5.0]	4.0 [3.0-5.0]	1.18	0.98-1.41	.085
Interference, *Md* [*IQR*]	**15.0 [6.0-30.5]**	**24.0 [13.0-32.0]**	**1.03**	**1.00-1.05**	**.034***

* p<0.05, **p<0.01

7.5.3 Physical variables

The results of univariable logistic regression analyses examining the predictive value of baseline physical variables in determining persistent chest pain are presented in Table 7.5. Participants with persistent chest pain were more likely to have reported heartburn at least once per month at baseline (OR=2.16, 95% CI 1.01-4.64, p=0.048). This relationship was maintained when employment status and patient type were controlled for in the analysis (OR=2.42, 95% CI 1.05-5.54, p=0.038). No other physical variables significantly predicted worsened pain, but there was a trend towards a higher proportion of participants with musculoskeletal-like pain with persistent symptoms.

Table 7.5 Logistic regression analyses of physical variables as predictors of persistent chest pain

Physical variables	Improved CP	Persistent CP	OR	95% CI	*p*
Heartburn (%)	**17 (25.8%)**	**24 (42.9%)**	**2.16**	**1.01-4.64**	**.048***
Acid reflux (%)	16 (24.6%)	16 (29.1%)	1.26	0.56-2.83	.581
Dysphagia (%)	6 (9.4%)	9 (17.3%)	2.02	0.67-6.11	.205
Musculoskeletal pain (%)	31 (46.3%)	36 (53.7%)	1.80	0.87-3.69	.110

* p<0.05

7.5.4 Emotional variables

Table 7.6 presents the results of the univariable logistic regression analyses examining the value of emotional variables in predicting persistent chest pain. Anxiety and depression levels were approximately one point higher on the 21-point scales for participants with persistent chest pain, yet these differences were neither statistically significant (OR=1.08, 95% CI 0.99-1.18, p=0.067 and OR=1.33, 95% CI 0.89-2.00, p=0.167, respectively) nor clinically significant (i.e. >1.5 difference). Significant differences in somatic symptom severity were not observed (OR=1.04, 95% CI 0.98-1.12, p=0.196), and the proportion indicating panic disorder did not differ significantly between groups either (OR=1.68, 95% CI 0.71-3.96, p=0.236).

Heart-focused anxiety as measured by the Cardiac Anxiety Questionnaire (CAQ) significantly predicted continued chest pain (OR=1.05, 95% CI 1.01-1.08, p=0.007). Two subscales of the CAQ were also significantly predictive: fear (OR 1.08, 95% CI 1.02-1.15, p=0.008) and attention (OR 1.16, 95% CI 1.05-1.28, p=0.005). The behavioural element to the questionnaire, i.e. avoidance of activities, was not predictive of symptom persistence, however. In a multivariate logistic regression analysis, cardiac anxiety remained predictive of persistent pain when employment status and patient type were controlled for (OR=1.05, 95% CI 1.01-1.08, p=0.025).

Table 7.6 Logistic regression analyses of emotional variables as predictors of persistent chest pain

Emotional variables	Improved CP	Persistent CP	OR	95% CI	*p*
Anxiety, *M* (*SD*)	7.03 (4.13)	8.37 (4.16)	1.08	0.99-1.18	.070
Depression, *Md* (IQR)	3.0 [1.0-6.0]	4.0 [2.0-7.0]	1.09	0.98-1.21	.112
Somatisation, *M* (*SD*)	8.97 (5.21)	10.16 (5.35)	1.04	0.98-1.12	.196
Panic (yes=1) (%)	12 (17.9)	15 (26.8)	1.68	0.71-3.96	.236
Cardiac anxiety, *M* (*SD*)	**24.97 (10.88)**	**30.55 (11.43)**	**1.05**	**1.01-1.08**	**.007****
Fear, *M* (*SD*)	**13.22 (6.22)**	**16.37 (6.54)**	**1.08**	**1.02-1.15**	**.008****
Avoidance, *M* (*SD*)	6.29 (4.94)	6.93 (4.70)	1.03	0.96-1.11	.453
Attention, *M* (*SD*)	**5.31 (3.17)**	**7.25 (4.16)**	**1.16**	**1.05-1.28**	**.005****

* p<0.05, **p<0.01

7.5.5 Cognitive variables

Five of the eight illness perceptions, as measured by the Brief Illness Perception Questionnaire (B-IPQ), significantly predicted persistent chest pain (see Table 7.7). Participants who perceived greater consequences (OR=1.21, 95% CI 1.05-1.38, p=0.007), a longer timeline (OR=1.17, 95% CI 1.04-1.31, p=0.010), greater illness identity (OR=1.37, 95% CI 1.13-1.65, p=0.001), larger concern (OR=1.22, 95% CI 1.06-1.39, p=0.005), and were more emotionally affected (OR=1.19, 95% CI 1.05-1.35, p=0.007), had higher odds of persistent symptoms. These illness perceptions continued to significantly predict persistent chest pain once employment status and patient type were controlled for (data not shown). Attributions to cardiac,

psychological, and other possible physical causes did not differ according to outcome status, but a higher attribution to a respiratory cause almost reached significance in predicting persistent chest pain (OR=1.22, 95% CI 1.00-1.48, p=0.050). However, a high proportion of participants found it difficult to rate attributions prior to receiving their test results, and 16-21% of participants were unable to answer these questions. The relationship between attributions and persistent pain is therefore difficult to ascertain and attributions will not be included in multivariate analyses.

Table 7.7 Logistic regression analyses of cognitive variables as predictors of persistent chest pain

Cognitive variables	n	Improved CP	Persistent CP	OR	95% CI	*p*
B-IPQ, *Md* [*IQR*]						
Consequences	**120**	**2.0 [1.0-5.0]**	**4.0 [2.0-6.0]**	**1.21**	**1.05-1.38**	**.007****
Timeline	**107**	**3.0 [1.0-6.0]**	**5.0 [3.0-9.3]**	**1.17**	**1.04-1.31**	**.010***
Personal control	117	2.0 [0.0-5.0]	2.5 [0.0-6.0]	1.06	0.94-1.19	.340
Treatment control	117	6.0 [4.0-9.0]	7.0 [5.0-9.25]	1.05	0.93-1.19	.418
Identity	**111**	**3.0 [2.0-5.0]**	**5.0 [3.0-7.0]**	**1.37**	**1.13-1.65**	**.001****
Concern	**122**	**5.0 [3.5-7.0]**	**8.0 [5.0-9.0]**	**1.22**	**1.06-1.39**	**.005****
Understanding	123	3.0 [1.0-6.5]	4.0 [2.0-5.3]	1.01	0.89-1.13	.936
Emotional affect	**122**	**3.0 [2.0-6.0]**	**6.0 [4.0-8.0]**	**1.19**	**1.05-1.35**	**.007****
IPQ-R Identity Score	116	1.0 [0.0-4.0]	3.0 [0.0-5.0]	1.10	0.97-1.25	.137
Attributions, *Md* [*IQR*]						
Cardiac	108	3.0 [1.0-5.0]	3.0 [2.0-5.0]	1.04	0.87-1.24	.688
Digestive	101	1.0 [1.0-4.0]	2.0 [1.0-4.0]	1.11	0.91-1.36	.303
Respiratory	100	1.0 [1.0-4.0]	3.0 [1.0-5.0]	1.22	1.00-1.48	.050
Psychological	103	2.0 [1.0-5.0]	3.0 [1.0-5.0]	1.07	0.90-1.27	.459

* p<0.05, **p<0.01

7.5.6 Social and service-related variables

A number of social and service-related variables were examined in relation to persistent NCCP (See Table 7.8). Higher satisfaction ratings with information provided at baseline were associated with a lower odds of persistent pain (OR=0.71, 95% CI 0.52-0.96, p=0.028). At follow up, participants who perceived that they had

received their test results were also less likely to report continued pain (OR=0.44, 95% CI 0.21-0.94, p=0.034). The other service-related variables assessed at baseline, which were not predictive of persistent chest pain, included test waiting time, previous tests, and prior explanation of angina. Exposure to heart disease was also examined, but was similarly not associated with continued pain. Satisfaction with information received was no longer predictive of persistent pain once employment status and patient type were controlled for (OR=0.78, 95% CI 0.56-1.08, p=0.126). Receipt of results did remain predictive, however, in a multivariate model controlling for employment and patient type (OR=0.33, 95% CI 0.14-0.80, p=0.013).

Table 7.8 Logistic regression analyses of social & service-related variables as predictors of persistent chest pain

Social & service-related variables	**Improved CP**	**Persistent CP**	**OR**	**95% CI**	***p***
Waiting time for EST, *Md [IQR]*	117 [1-126]	120 [1-127]	1.00	1.00-1.01	.864
Previous cardiac tests, n (%)					
Previous EST	16 (25.4%)	12 (26.1%)	1.04	0.44-2.47	.935
Previous angiogram	10 (15.9%)	7 (15.2%)	0.95	0.33-2.72	.926
Explanation of angina, n (%)	7 (10.4%)	12 (20.7%)	2.24	0.82-6.13	.118
Family History, n (%)					
Parents	29 (58.0%)	30 (68.2%)	1.55	0.67-3.62	.309
Others	14 (37.8%)	12 (38.7%)	1.04	0.39-2.77	.941
Friends	6 (14.6%)	5 (13.5%)	0.91	0.25-3.28	.887
Satisfaction with info, Md [IQR]	**4.0 [3.0-4.0]**	**3.0 [1.0-4.0]**	**0.71**	**0.52-0.96**	**.028***
Consistency of info, Md [IQR]	3.5 [3.0-4.0]	3.0 [2.0-4.0]	0.85	0.61-1.18	.327
Receipt of results, n (%)	**56 (77.8%)**	**37 (60.7%)**	**0.44**	**0.21-0.94**	**.034***

* p<0.05

7.5.7 Multivariate logistic regression model

All variables that predicted persistent chest pain at univariate level with a p value less than 0.15 were entered into a multivariate regression model. The emotional variable cardiac anxiety was not entered in the model since the two subscales fear and attention were composites of this variable, and inclusion would therefore

cause the problem of singularity. All variables with *p*-values less than 0.15 were retained in the model and variables whose *p*-values increased to greater than 0.15 were excluded, as recommended by guidelines (Bursac et al., 2008; Hosmer & Lemeshow, 1999). Table 7.9 summarises the multivariate analysis produced.

The model was statistically significant (χ^2=20.45, df=5, *p*=0.001) and the Hosmer and Lemeshow Test had a significance value greater than 0.05, indicating a good model fit (χ^2=7.48, df=7, *p*=0.381).

Table 7.9 Multivariate logistic regression analysis of predictors of persistent chest pain

Variables	OR	95% CI	*p*
Demographic			
Employed	0.36	0.13-1.01	.052
Physical			
Heartburn	**3.01**	**1.14-8.00**	**.027***
Service-related			
Inpatient	1.25	0.39-4.08	.706
Receipt of results	**0.36**	**0.13-0.98**	**.045***
Cognitive			
Timeline	**1.18**	**1.02-1.37**	**.027***

* *p*<0.05

As can be seen from Table 7.9, three variables made uniquely significant contributions to the model. Participants with heartburn at baseline were more likely to report persistent pain at multivariate level (OR=3.01, 95% CI 1.14-8.00, *p*=0.027), and participants who perceived to have received their results were less likely to report persistent pain (OR=0.36, 95% CI 0.13-0.98, *p*=0.045). In addition, a perception at baseline that the chest pain would last for a longer timeline was associated with greater odds of persistent chest pain (OR=1.18, 95% CI 1.02-1.37, *p*=0.027). Participants who were employed had lower odds of reporting persistent pain, a difference that almost reached statistical significance at multivariate level.

7.6 Summary

This chapter reported on the longitudinal findings of the prospective cohort study and reported on the primary outcome variable of persistent chest pain at one-year follow-up. The findings can be summarised as follows:

- Only eleven participants were lost to follow-up and their profile was similar to participants, except analyses indicated a possible participation bias towards lower levels of psychological morbidity.
- Nearly one third (30%) of participants reported they did not receive the results of their exercise stress test and almost two thirds (64%) stated that they were not given an explanation for their chest pain.
- Chest pain improved in just over half of participants (54.5%). Nearly half (45.5%) reported it at a frequency of at least once a month, however. These participants were labelled as experiencing persistent pain. One in seven continued to experience severe pain.
- Participants who were employed, had a higher frequency of chest pain at baseline, and higher levels of pain interference were more likely to report persistent pain.
- Presence of heartburn at a frequency of at least once per month at baseline was associated with persistent pain, while controlling for employment status and patient type (outpatient/inpatient).
- The emotional variables anxiety, depression, somatisation, and panic did not predict persistent pain, but a non-significant trend for higher levels of emotional variables in participants with persistent pain was observed.
- Cardiac anxiety was significantly associated with persistent pain, while controlling for employment status and patient type.
- Participants who perceived greater consequences, a longer timeline, greater illness identity, larger concern, and were more emotionally affected were more likely to report persistent pain.

- A perceived lack of receipt of test results at follow-up was also associated with persistent chest pain when controlling for employment status and patient type.
- A multivariate logistic regression model including employment status, heartburn, patient type (inpatient/outpatient), receipt of test results, and perception of timeline, was statistically significant (χ^2=20.45, df=5, p=0.001). Heartburn, receipt of results, and perception of timeline made significantly unique contributions to the model.

Chapter 8: Prospective Cohort Study – Healthcare Utilisation

8.1 Introduction

The previous chapter reported on the outcome of persistent chest pain and baseline variables that were predictive of this persistence. This chapter reports on the second outcome variable of persistent health service use. Levels of healthcare utilisation during the one-year follow-up period were assessed. The proportion of participants who continued to attend healthcare settings and receive further testing is reported. While over two thirds of participants reported continued chest pain, only 40% of these participants sought ongoing medical help. Analysis on the prediction of persistent health service use for chest pain will then be presented. The ability of demographic, physical, emotional, cognitive, social, and service-related variables to predict use of health services was examined and the results will be presented.

8.2 Health service use

8.2.1 Healthcare visits

Participants reported on their healthcare visits for the purpose of chest pain during the one-year follow-up period, the results of which is summarised in Table 8.1. Almost one in ten participants (9%) returned to the emergency department for the investigation of chest pain. The majority returned once, one participant returned five times, and another returned nine times. Slightly less than half of participants (47%) returned to their general practitioner for the primary symptom of chest pain. Most of these participants returned for one visit (21%). However, 8% returned for two visits, 10% for three visits, and the remaining 9% returned four times or more. The majority of emergency department attendees also attended their general practitioner (7 out of 11). Just over half of participants (51%) visited a cardiology clinic, most of whom attended once (34%) and the remainder attended twice or

three times (18%). Other specialists attended included gastroenterologists (8%) and respiratory specialists (4%). One participant attended an alternative therapist and another attended a pain clinic.

Differences in healthcare use between participants with and without any further chest pain at follow-up were examined. Unsurprisingly, only participants with continued chest pain attended the emergency department during the follow-up period (p=0.033, Fisher's exact test). In addition, they were more likely to attend a cardiology clinic (OR=3.01, 95% CI 1.34-6.76, p=0.006) and to be waiting for a future clinic appointment (OR=6.63, 95% CI 1.88-23.29, p=0.003). No differences were found between the groups regarding visitation to primary care or other specialists.

Table 8.1 Healthcare visits relating to chest pain during the one-year follow-up period

Healthcare Visits n (%)	Total n=134	No CP n=42 (31%)	Persistent CP n=92 (69%)	OR	*p*
Emergency department[Φ]	**11 (8.9%)**	**0**	**11 (12.6%)**	-	**.033***
General Practitioner (x1)	59 (47.2%)	14 (37.8%)	45 (51.1%)	1.72	.176
Cardiology clinic	**64 (51.2%)**	**12 (32.4%)**	**52 (59.1%)**	**3.01**	**.006****
Other specialist	16 (11.9%)	2 (4.8%)	14 (15.2%)	3.59	.102
Gastroenterologist	10 (7.5%)	2 (4.8%)	8 (8.7%)	1.91	.724
Respiratory clinic[Φ]	5 (3.7%)	0	5 (5.4%)	-	.325
Alternative therapist[Φ]	1 (0.7%)	0	1 (1.1%)	-	1.00
Pain clinic[Φ]	1 (0.7%)	0	1 (1.1%)	-	1.00
Waiting for clinic	**34 (28.1%)**	**3 (8.1%)**	**31 (36.9%)**	**6.63**	**.001****

* <0.05, **<0.01
[Φ] Fischer's exact test used

8.2.2 Healthcare tests

Healthcare testing figures during the one-year follow-up are displayed in Table 8.2. Nearly one half of participants (46%) were referred for further cardiac tests including angiograms (23%), echocardiograms (19%), holter monitoring (10%), electrocardiograms (10%), exercise stress tests (3%), tilt table tests (2%), and loop recorders (2%). Differences in referrals to further cardiac testing were not found

between participants with no further pain and those with continued pain. One in ten was referred for radiography tests, 8% were referred for gastrointestinal tests, and 5% were referred for respiratory tests. Participants with persistent pain were not more likely to be referred for further radiography, gastrointestinal, or respiratory testing. Approximately one in six (17%) were waiting for further testing, which was more likely for participants with continued pain (OR=10.52, 95% CI 1.35-81.88, p=0.025).

Table 8.2 Healthcare tests during the one-year follow-up period

Tests n (%)	Total	No CP	Persistent CP	OR	*p*
Cardiac tests	56 (46.3%)	15 (40.5%)	41 (48.8%)	1.40	.401
Exercise stress test	4 (3.3%)	1 (2.7%)	3 (3.6%)	1.33	.806
Angiogram	28 (23.1%)	6 (16.2%)	22 (23.1%)	1.83	.235
Echo	26 (19.4%)	6 (14.3%)	20 (21.7%)	1.67	.315
Holter	13 (9.7%)	3 (7.1%)	10 (10.9%)	1.59	.502
ECG	13 (9.7%)	1 (2.4%)	12 (13.0%)	6.15	.086
Tilt table test[Φ]	2 (1.5%)	0	2 (2.2%)	-	1.00
Loop recorder[Φ]	2 (1.5%)	0	2 (2.2%)	-	1.00
Radiography tests	14 (10.4%)	1 (2.4%)	13 (14.1%)	6.75	.070
Xray / Ultrasound	10 (7.5%)	1 (2.4%)	9 (9.8%)	2.29	.130
MRI[Φ]	3 (2.2%)	0	3 (3.3%)	-	.237
Body scan[Φ]	1 (0.7%)	0	1 (1.1%)	-	.498
Gastrointestinal testing	11 (8.2%)	2 (4.8%)	9 (9.8%)	0.97	.326
Gastroscopy	8 (6.0%)	1 (2.4%)	7 (7.6%)	1.40	.236
Endoscopy	2 (1.5%)	1 (2.4%)	1(1.1%)	0.33	.567
Colonoscopy	3 (2.2%)	1 (2.4%)	2 (2.2%)	0.01	.940
Duplex abdomen scan[Φ]	1 (0.7%)	0	1 (1.1%)	-	.498
Respiratory testing					
- Pulmonary function test	7 (5.2%)	2 (4.8%)	5 (5.4%)	0.03	.871
Waiting for further tests	**20 (16.5%)**	**1 (2.7%)**	**19 (22.6%)**	**10.52**	**.007***

* p<0.05
[Φ] Fischer's exact test used

8.3 Predicting persistent health service use

The following section reports on the prediction of persistent health service use. The sample was categorised into the following three categories: participants with no further chest pain; participants with continued chest pain but no persistent health service use; and participants with continued chest pain and persistent health

service use. Since continuing health service use is dependent upon having continuing symptoms, participants with chest pain who did and did not continue to use services for the investigation of their pain needed to be examined separately. This categorisation enabled the examination of differences between participants with no further pain, and those with or without persistent health service use for the investigation of their persistent chest pain. These categories will from this point be labelled as: 1) no chest pain; 2) chest pain only (CP only); and 3) chest pain and health service use (CP & HSU). There were 42 (32%), 53 (41%), and 35 (27%) in each category, respectively. Approximately 40% of participants with continued chest pain were classed as persistent health service users.

Persistent health service use was classified as unscheduled visitation to the emergency department and/or general practitioner for the investigation of chest pain. Other health service use in the follow-up period was not included, since referral for testing and clinic appointments was determined by their doctor and was generally outside of the patient's control. Participants who made only one visit to the general practitioner for the investigation of chest pain were not considered persistent health service users since many returned to their doctor in order to receive test results. Indeed, 27% of those without further pain returned to their general practitioner just once. In comparison, 17% of participants with persistent pain returned to their general practitioner only once, while 35% attended twice or more. Only three participants with persistent pain exclusively attended the emergency department, and the remaining seven who re-attended the emergency department also sought care with their primary care physician. Two fifths of participants with ongoing chest pain solely attended their general practitioner. Overall, 40% of participants with persistent chest pain sought ongoing medical care.

Health service use data was missing for four of the participants at follow-up and the total sample is therefore 130. Multinomial logistic regression analyses were conducted to determine which variables were able to distinguish between these three groups.

8.3.1 Demographic variables

Demographic variables were firstly considered as potential predictors of persistent health service use. The results of univariate multinomial logistic regression analyses are presented in Table 8.3, which examine the predictive value of the demographic variables in differentiating between participants with no chest pain, participants with persistent chest pain, and participants with persistent chest pain and health service use. Neither gender, age, marital status, education level, nor health insurance ownership discriminated between the three groups (p>0.05). Participants who were recruited as inpatients, in comparison to outpatients, were less likely to have persistent chest pain (OR=0.33, 95% CI 0.13-0.23, p=0.023), and were also less likely to re-attend health services for the investigation of their pain (OR=0.27, 95% CI 0.09-0.84, p=0.024).

Table 8.3 Multinomial regression analyses of demographic variables as predictors of persistent chest pain and health service use

	CP only^		CP & HSU^	
Demographic variables	**OR (95% CI)**	***p***	**OR (95% CI)**	***p***
Age	1.00 (0.97-1.03)	.727	1.00 (0.97-1.04)	.806
Male	1.12 (0.50-2.52)	.784	1.50 (0.61-3.72)	.381
Marital status				
Single	1.67 (0.21-13.22)	.629	1.50 (.20-11.09)	.691
Married	0.64 (0.16-2.54)	.528	0.65 (0.18-2.38)	.514
Separated/Widowed	1.00		1.00	
Education				
Primary	1.06 (0.40-2.82)	.906	9.88 (0.30-2.59)	.816
Secondary	1.31 (0.36-4.73)	.681	0.73 (0.16-3.38)	.691
Tertiary	1.00		1.00	
Employed	0.54 (0.20-1.51)	.243	**0.28 (0.10-0.84)**	**.023***
Medical card	1.66 (0.66-4.18)	.282	**3.32 (1.22-9.03)**	**.019***
Insurance	0.99 (0.41-2.41)	.982	0.59 (0.22-1.63)	.311
Inpatient	**0.33 (0.13-0.86)**	**.023***	**0.27 (0.09-0.84)**	**.024***

* <0.05, **<0.01

^ Reference category: No chest pain

Although being employed or having a medical card did not predict participants with persistent chest pain compared to those without, these variables did predict the participants with persistent chest pain and persistent health service use. Employed participants had a lower odds of re-attending health services for their chest pain (OR=0.28, 95% CI 0.10-0.84, p=0.023). In addition, participants with a medical card were more likely to re-attend health services (OR=3.32, 95% CI 1.22-9.03, p=0.019). Since medical card ownership is based on income, it is highly correlated with employment status (rho= -0.39, p<0.001). The variable employment status will be retained for use in the multivariate model (see section 8.3.7).

8.3.2 Chest pain variables

As can be seen in Table 8.4, baseline measures of chest pain frequency, severity, duration, commencement, and interference did not significantly predict persistent chest pain only. However, chest pain frequency, commencement, and interference were all predictive of persistent health service use for participants with continued chest pain. A higher odds of continued health service use was found for participants with a higher frequency of symptoms at baseline (OR=1.45, 95% CI 1.04-2.03, p=0.030), participants with longer time since commencement of symptoms (OR=1.37, 95% CI 1.06-1.77, p=0.018), and greater perceived interference of symptoms (OR=1.39, 95% CI 1.07-1.80, p=0.015). Although these variables did not predict chest pain only, the effect sizes are only slightly smaller and might have reached significance with a larger sample. When employment status and patient type were controlled for, pain interference continued to predict persistent pain and service use (OR=1.04, 95% CI 1.00-1.07, p=0.047), but pain commencement (OR=1.13, 95% CI 0.81-1.59, p=0.470) and pain frequency (OR=1.39, 95% CI 0.96-2.01, p=0.081) did not.

Table 8.4 Multinomial regression analyses of chest pain variables as predictors of persistent chest pain and health service use

	CP only^		CP & HSU^	
Chest pain variables	**OR (95% CI)**	***p***	**OR (95% CI)**	***p***
Frequency	1.24 (0.93-1.65)	**.150**	**1.45 (1.04-2.03)**	**.030***
Severity	0.69 (0.39-1.21)	.194	1.15 (0.62-2.12)	.654
Duration	0.84 (0.66-1.08)	.176	0.97 (0.74-1.27)	.806
Commencement	1.21 (0.97-1.53)	**.095**	**1.37 (1.06-1.77)**	**.018***
Interference	0.99 (0.97-1.03)	**.888**	**1.03 (1.00-1.06)**	**.033***

* <0.05, **<0.01
^ Reference category: No chest pain

8.3.3 Physical variables

The results of univariate analyses examining the association of physical variables at baseline with persistent health service use are displayed in Table 8.5. In comparison to participants with no further chest pain, the only physical variable that predicted persistent chest pain with or without persistent health service use was musculoskeletal pain. Participants indicating musculoskeletal-like pain, i.e. pain worse on movement, were three times more likely to report persistent chest pain only (OR=3.09, 95% CI 1.25-7.62, *p*=0.014) and almost four times more likely to have persistent chest pain and health service use (OR=3.83, 95% 1.40-10.48, *p*=0.009). Over two thirds of participants who indicated musculoskeletal-like pain at baseline had persistent chest pain and health service use, compared to 35% who reported no further chest pain. Although heartburn at a monthly frequency at baseline was not predictive of persistent chest pain only (OR=1.11, 95% CI 0.42-2.92, *p*=0.840), it was predictive of persistent healthcare-seeking behaviour for chest pain (OR=3.38, 95% CI 1.23-9.28, *p*=0.018). Over half of participants who continued to use services for the investigation of chest pain had heartburn at baseline at a frequency of at least once per month, compared to 25% of participants with no further chest pain.

None of the other physical variables significantly differed across the groups. When heartburn and musculoskeletal pain were examined while controlling for patient type and employment status, heartburn continued to predict persistent pain and health service use (OR=3.62, 95% CI 1.15-11.39, *p*=0.028), and musculoskeletal pain continued to predict both chest pain only (OR=2.89, 95% CI 1.09-7.67, *p*=0.033) and chest pain and health service use (OR=4.46, 95% CI 1.43-13.90, *p*=0.010).

Table 8.5 Multinomial regression analyses of physical variables as predictors of persistent chest pain and health service use

	CP only^		CP & HSU^	
Physical variables	**OR (95% CI)**	***p***	**OR (95% CI)**	***p***
Heartburn	1.11 (0.42-2.92)	.840	**3.38 (1.23-9.28)**	**.018***
Acid reflux	0.79 (0.29-2.18)	.655	1.58 (0.56-4.43)	.389
Dysphagia	1.17 (0.26-5.28)	.834	2.78 (0.65-11.85)	.166
Musculoskeletal pain	**3.09 (1.25-7.62)**	**.014***	**3.83 (1.40-10.48)**	**.009****

* <0.05, **<0.01

^ Reference category: No chest pain

8.3.4 Emotional variables

The baseline emotional variables were all examined as predictors of group membership, the results of which are presented in Table 8.6. Emotional variables did not differentiate between participants with no further pain and those with continued chest pain. However, anxiety, depression, and cardiac anxiety were all predictive of healthcare-seeking behaviour for continued symptoms. The higher the anxiety score at baseline, the higher the odds of persistent health service use (OR=1.18, 95% CI 1.05-1.32, *p*=0.007), and higher depression scores were also predictive of health service use (OR=1.22, 95% CI 1.06-1.42, *p*=0.007). Anxiety and depression scores were on average 2.7 and 2.2 scores higher, respectively, for participants with persistent chest pain and health service use, compared to those with no further pain.

Heart-focused anxiety, as measured by the CAQ, was also significantly predictive of persistent chest pain and health service use (OR=1.10, 95% CI 1.05-1.16, $p<0.001$), as was each of its subscales. On average, mean scores on the CAQ at baseline were 11 points higher for those who continued to use health services for the investigation of their chest pain. Although levels of somatisation did not differ significantly between groups, mean scores on the PHQ-15 rose from 8.4 (SD=5.0) in participants with no pain to 9.6 (SD=5.58) in participants with chest pain only, and to 10.4 (SD=5.1) in participants with persistent health service use. Levels of panic were similarly not statistically significant between groups, although 29% of persistent healthcare users for chest pain indicated a high likelihood of panic disorder at baseline, compared to 14% with no further chest pain.

The emotional variables were also examined while controlling for patient type and employment status, and the same pattern emerged. Anxiety and depression scores continued to predict persistent chest pain and health service use when compared to participants with no chest pain at follow up (OR=1.23, 95% CI 1.07-1.41, $p=0.004$ and OR=1.25, 95% CI 1.06-1.48, $p=0.010$, respectively). Cardiac anxiety also continued to predict persistent pain and service use (OR=1.10, 95% CI 1.04-1.16, $p=0.001$), as did the subscales fear and attention, and the subscale avoidance almost reached significance (OR=1.11, 95% CI 0.99-1.25, $p=0.064$).

Table 8.6 Multinomial regression analyses of emotional variables as predictors of persistent chest pain and health service use

	CP only^		CP & HSU^	
Emotional variables	**OR (95% CI)**	***p***	**OR (95% CI)**	***p***
Anxiety	1.07 (0.96-1.19)	.200	**1.18 (1.05-1.32)**	**.007****
Depression	1.06 (0.92-1.22)	.405	**1.22 (1.06-1.42)**	**.007***
Somatisation	1.05 (0.96-1.14)	.283	1.08 (0.98-1.18)	.107
Panic	1.86 (0.59-5.84)	.288	2.54 (0.75-8.61)	.136
Cardiac anxiety	1.02 (0.98-1.06)	.343	**1.10 (1.05-1.16)**	**.000*****
Fear	1.03 (0.96-1.10)	.379	**1.14 (1.05-1.23)**	**.002****
Avoidance	0.99 (0.91-1.08)	.839	**1.11 (1.00-1.23)**	**.044***
Attention	1.14 (1.00-1.29)	.052	**1.32 (1.14-1.53)**	**.000*****

* <0.05, **<0.01, ***<0.001
^ Reference category: No chest pain

8.3.5 Cognitive variables

Illness perceptions and illness attributions were not predictive of continued chest pain without healthcare-seeking behaviour when compared to participants with no chest pain, as demonstrated in Table 8.7. Yet perceptions of consequences, timeline, identity, illness concern, and emotional affect, as measured by the B-IPQ, were significantly predictive of continued pain with persistent service use. The odds of persistent service use for chest pain increased when greater consequences were perceived (OR=1.35, 95% CI 1.12-1.64, p=0.002), chest pain was expected to last for a longer time into the future (OR=1.26, 95% CI 1.07-1.39, p=0.005), greater illness identity was reported (OR=1.40, 95% CI 1.10-1.79, p=0.006), more illness concern was expressed (OR=1.30, 95% CI 1.08-1.58, p=0.006), and elevated emotional affect was conveyed (OR=1.33, 95% CI 1.12-1.59, p=0.001). Since the perception of timeline could be influenced by the time when chest pain commenced, it was examined while controlling for the commencement of pain. The perception of timeline still significantly predicted persistent chest pain and health service use (OR=1.23. 95% CI 1.02-1.37, p=.027). Differences in the number of cardiac-related symptoms that were endorsed as being related to participants' NCCP, as measured by the IPQ-R identity score, did not differ between groups. This

suggests that participants are potentially endorsing more non-cardiac symptoms on the identity measure on the B-IPQ, rather than cardiac symptoms (see section 6.3.5.1).

Illness perceptions were also examined while controlling for patient type and employment status. The perception of greater consequences (OR=1.33, 95% CI 1.08-1.63, p=0.007), longer timeline (OR=1.23, 95% CI 1.03-1.46, p=0.024), greater illness identity (OR=1.45, 95% CI 1.11-1.90, p=0.007), more illness concern (OR=1.37, 95% CI 1.10-1.70, p=0.005), and elevated emotional affect (OR=1.33, 95% CI 1.10-1.61, p=0.004) remained predictive of persistent chest pain and health service use while controlling for these variables. These illness perceptions do not distinguish participants who have continued symptoms from those who do not, but do identify those who continue to seek medical help for their chest pain.

When illness attributions were examined, participants who were more likely to endorse a psychological attribution at baseline, were more likely to have persistent pain and service use, compared to those without further NCCP (OR=1.28, 95% CI 1.01-1.64, p=0.046), and the association with attribution to a respiratory cause almost reached significance. None of the attributions were significantly associated with chest pain and related service use when employment status and patient type were controlled for, but attribution to a psychological cause was almost statistically significant (OR=1.31, 95% CI 1.00-1.71, p=0.051).

Table 8.7 Multinomial regression analyses of cognitive variables as predictors of persistent chest pain and health service use

		CP only^		CP & HSU^	
Cognitive variables	**n**	**OR (95% CI)**	***p***	**OR (95% CI)**	***p***
B-IPQ					
Consequences	120	1.00 (0.84-1.19)	.994	**1.35 (1.12-1.63)**	**.002****
Timeline	107	1.07 (0.93-1.24)	.351	**1.26 (1.07-1.39)**	**.005****
Personal control	117	0.91 (0.79-1.05)	.182	0.92 (0.78-1.08)	.288
Treatment control	117	0.96 (0.83-1.11)	.545	1.01 (0.85-1.20)	.888
Identity	111	1.03 (0.84-1.27)	.780	**1.40 (1.10-1.79)**	**.006****
Concern	122	1.04 (0.89-1.21)	.640	**1.30 (1.08-1.58)**	**.006****
Understanding	123	0.96 (0.83-1.10)	.519	0.95 (0.81-1.11)	.496
Emotional affect	122	1.11 (0.96-1.29)	.159	**1.33 (1.12-1.59)**	**.001*****
IPQ-R Identity Score	116	1.14 (0.97-1.33)	.108	1.05 (0.88-1.26)	.572
Attributions					
Cardiac	108	0.84 (0.67-1.05)	.133	1.13 (0.89-1.43)	.327
Digestive	101	1.02 (0.78-1.32)	.910	1.28 (0.97-1.68)	.083
Respiratory	100	1.03 (0.80-1.32)	.839	1.30 (0.99-1.70)	.059
Psychological	103	0.99 (0.80-1.24)	.957	**1.28 (1.01-1.64)**	**.046***

* <0.05, **<0.01
^ Reference category: No chest pain

8.3.6 Social and service-related variables

The ability of social and service-related variables to distinguish between the three groups was also examined, as shown in Table 8.8. An increase of one day in waiting time for exercise stress testing was associated with a marginally higher odds of experiencing continued chest pain (OR=1.01, 95% CI 1.00-1.02, *p*=0.011) and persistent chest pain and service use (OR=1.01, 95% CI 1.00-1.02, *p*=0.020). Since participants with shorter waiting times were inpatients, the variable inpatient was controlled for and the relationship between waiting time and persistent service use was no longer significant (OR=1.00, 95% CI 0.99-1.02, *p*=0.834).

Participants who had an EST prior to recruitment at baseline were less likely to report persistent chest pain only (OR=0.23, 95% CI 0.07-0.73, *p*=0.013), compared to participants without further chest pain, yet no difference was found for

participants with persistent pain and service use. When patient type and employment status were controlled for, the effect size remained significant (OR=0.16, 95% CI 0.04-0.60, p=0.013). A prior angiogram did not predict chest pain only however, although only 17 of follow-up participants had an angiogram prior to baseline assessment.

While having at least one parent with a medical history of heart disease predicted persistent chest pain only (OR=2.92, 95% CI 1.05-2.93, p=0.040), it did not predict persistent chest pain and service use, when compared to participants without further chest pain. It remained predictive of chest pain only when employment status and patient type were controlled for (OR=3.64, 95% CI 1.20-11.05, p=0.022). Differences were not found for participants with a history of heart disease in other members of their families or their friends.

Participants who were less satisfied with the information provided by medical providers at baseline were more likely to have persistent chest pain and service use, but this association did not remain statistically significant when employment status and patient type were controlled for (OR=0.71, 95% CI 0.46-1.11, p=0.130). Neither a prior explanation of angina nor perceived consistency of information from service providers were significantly related to future chest pain only or persistent chest pain and service use. While the receipt of test results did not significantly differentiate the three categories of participants examined, the receipt of results almost reached significance in predicting persistent chest pain and service use (OR=0.39, 95% CI 0.14-1.06, p=0.066).

Table 8.8 Multinomial regression analyses of service-related variables as predictors of persistent chest pain and health service use

Social & service-related variables	CP only^		CP & HSU^	
	OR (95% CI)	*p*	OR (95% CI)	*p*
Waiting time for EST	**1.01 (1.00-1.02)**	**.011***	**1.01 (1.00-1.02)**	**.020***
Previous cardiac tests				
Previous EST	**0.23 (0.07-0.73)**	**.013***	1.32 (0.47-3.72)	.602
Previous angiogram	1.13 (0.29-4.37)	.855	2.71 (0.70-10.47)	.148
Explanation of angina	0.47 (0.07-2.94)	.417	2.24 (0.49-10.24)	.297
Family history				
Parents	**2.92 (1.05-8.10)**	**.040***	2.07 (0.68-6.34)	.203
Others	0.90 (0.28-2.93)	.859	0.94 (0.24-3.77)	.934
Friends	1.53 (0.27-8.70)	.630	1.68 (0.25-11.27)	.595
Satisfaction with info	0.83 (0.57-1.21)	.330	**0.65 (0.43-0.98)**	**.038***
Consistency of info	0.98 (0.65-1.46)	.901	0.73 (0.47-1.13)	.157
Receipt of results	0.69 (0.27-1.79)	.445	0.39 (0.14-1.06)	.066

* <0.05, **<0.01

^ Reference category: No chest pain

8.3.7 Multivariate multinomial regression model

All variables in the previous univariate multinomial logistic regression analyses with *p*-values less than 0.15 for the categories chest pain only and/or chest pain and health service, when adjustments for employment status and patient type were made, were entered into a multivariate model. The model encompassed all domains, i.e. demographic, physical, emotional, cognitive, social, and service-related variables. All variables with *p*-values less than 0.15 were retained in the model and variables whose *p*-values increased to greater than 0.15 were excluded, as recommended by guidelines (Bursac et al., 2008; Hosmer & Lemeshow, 1999). The following multivariate model was produced (see Table 8.9).

Table 8.9 Multivariate multinomial regression analysis of predictors of persistent chest pain and health service use

	CP only^		CP & HSU^	
Variables	**OR (95% CI)**	***p***	**OR (95% CI)**	***p***
Demographic				
Employed	0.36 (0.10-1.30)	.119	**0.19 (0.04-0.82)**	**.026***
Physical				
Heartburn	1.28 (0.39-4.16)	.682	3.49 (0.91-13.34)	.068
Musculoskeletal	2.75 (0.95-7.97)	.063	2.88 (0.77-10.73)	.115
Emotional				
Cardiac anxiety	1.00 (0.96-1.05)	.947	**1.08 (1.01-1.13)**	**.020***
Service-related				
Inpatient	**0.23 (0.07-0.69)**	**.009****	**0.13 (0.03-0.64)**	**.012***

* <0.05, **<0.01
^ Reference category: No chest pain

The overall model was statistically significant (χ^2=37.24, df=10, p<0.001). Three variables were significant predictors of chest pain with persistent health service use when compared to participants with no chest pain. Participants who were employed (OR=0.19, 95% CI 0.04-0.82, p=0.026) and were recruited as inpatients (OR=0.13, 95% CI 0.03-2.24, p=0.023) were less likely to seek medical care for their chest pain, while participants with higher levels of cardiac anxiety (OR=1.08, 95% CI 1.01-1.13, p=0.020) had a higher odds of persistent pain and service use. Inpatients were also less likely to report persistent pain in the absence of service use (OR=0.23, 95% CI 0.07-0.69, p=0.009). The physical variable musculoskeletal-like pain almost reached significance in predicting persistent chest pain only, and heartburn almost reached significance in predicting persistent chest pain and health service use.

8.3.8 Reassurance

At follow up, participants' reassurance about their heart was assessed and this was examined to establish its relationship to chest pain and healthcare-seeking behaviour. Participants with persistent chest pain with and without persistent

health service use were compared to participants without further chest pain in a multinomial logistic regression analysis. As displayed in Table 8.10, higher reassurance scores were associated with lower odds of having persistent chest pain and having persistent pain and service use. For every unit increase in the reassurance score, the odds of persistent health service use decreased by 15% (OR=0.85, 95% CI 0.79-0.91, p<0.001).

Table 8.10 Multinomial regression analysis of reassurance as a predictor of persistent chest pain and health service use

	CP only^		CP & HSU^	
	OR (95% CI)	***p***	**OR (95% CI)**	***p***
Reassurance	**0.92 (0.87-0.97)**	**.004****	**0.85 (0.79-0.91)**	**.000*****

* <0.05, **<0.01
^ Reference category: No chest pain

It is understandable that participants without further chest pain would be more reassured about their heart. In order to examine whether participants who were more reassured about their heart were less likely to seek help for their pain, participants with chest pain and persistent health service use was used as the reference category in the multinomial logistic regression analysis. This allowed for comparison between the categories chest pain only and chest pain and health service use. Indeed, participants with chest pain only had higher reassurance scores than participants with chest pain and health service use (OR=1.08, 95% CI 1.02-1.15, p=0.005).

8.4 Summary

This chapter mainly reported on the outcome variable of health service use during the one-year follow-up period. The findings can be summarised as follows:

- Approximately half of participants sought further care from their general practitioners (47%) and attended cardiology clinics (51%).

- Of those with persistent chest pain symptoms, 40% sought ongoing medical care.
- One in ten attended the emergency department in the intervening year and nearly half (46%) of the sample were referred for further cardiac testing.
- At univariate and multivariate levels, participants who were employed were less likely to have persistent healthcare-seeking behaviour.
- Inpatients were less likely to have both persistent chest pain and persistent chest pain with associated health service use.
- Baseline symptom measures of frequency, commencement, and interference were predictive of persistent chest pain and health service use at univariate level, but not at multivariate level.
- Regarding physical variables, heartburn was predictive of persistent chest pain and health service use both at univariate and multivariate levels. Musculoskeletal pain was predictive of persistent symptoms, but was no longer predictive of persistent chest pain and health service use when included in the final multivariate model.
- At univariate level, a number of emotional variables were predictive of healthcare-seeking behaviour including anxiety, depression, and cardiac anxiety. In the final multivariate model, higher cardiac anxiety scores remained predictive of persistent chest pain and health service use.
- Five illness perceptions were associated with persistent health service use, namely, perceptions of consequences, timeline, identity, illness concern, and emotional affect. These remained significantly associated when employment status and patient type were controlled for.
- The receipt of test results was not significantly associated with lower odds of persistent chest pain and health service use, but the association almost reached significance.
- Participants who reported feeling reassured that they did not have a heart condition were less likely to have reported seeking subsequent help for their chest pain.

Chapter 9: Qualitative Study

9.1 Introduction

The following chapter presents the analysis of the qualitative study exploring how participants interpret chest pain in the context of normal test results and their experiences with the health services. Data gathering and analysis was informed by the principles of Interpretative Phenomenological Analysis (IPA). IPA is dedicated to the subjective experience of the participant and adopts an idiographic, phenomenological perspective. The analysis produced three super-ordinate themes, each encompassing four sub-themes. A detailed account of the IPA approach and the themes produced by the analysis will be presented in this chapter.

9.2 Aim of qualitative study

The aim of the qualitative study was to explore the understandings and experiences of patients with chest pain, in the context of receiving normal cardiac test results. The analysis examined how their chest pain was interpreted and understood within this context. Participants' interactions with health services and how these interactions may have influenced their interpretations were also explored.

9.3 Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA) was chosen as the research methodology due to its consistency with the research aim of understanding the personal meaning and sense-making of individuals who share a particular experience (Smith, Flowers, & Larkin, 2009). IPA is an approach to qualitative research concerned with the detailed examination of human lived experience. It aims to understand the 'lived' experience of participants by accessing the meaning they impress upon these experiences. In order to access this meaning, IPA considers

that the analyst must engage in interpretive work, and provides a systematic approach to achieving this (Smith et al., 2009; Smith & Osborn, 2007). The approach has been described as helping to bring "real life back into psychology as applied to health and medicine" (Kaptein, 2011, p.39)

IPA was chosen over other qualitative approaches due to its focus on understanding the self and personal meaning-making in addition to its usefulness for understanding phenomena which are dynamic and contextual (Smith et al., 2009). It is primarily used to examine illness experience (Smith, 2011). The method has been used extensively within health psychology to study a wide variety of topics. Discursive approaches were not considered relevant alternatives for this study due to their focus on understanding the cultural resources drawn upon in conversation to achieve certain functions. The use of grounded theory was also considered. Grounded theory also adopts an inductivist approach, but it engages with data at a higher conceptual level and aims to achieve an explanatory account of a phenomenon (Smith et al., 2009). This study was more explorative, however, and the emphasis was on understanding the complexity of the phenomenon as opposed to developing theoretical claims.

IPA developed in the mid-1990s but is committed to three theoretical perspectives with much longer histories, namely, phenomenology, hermeneutics and idiography (Smith et al., 2009). Phenomenology is the philosophical approach to the study of experience. IPA shares the phenomenological approach to understanding experience as being concerned with the meaning-making activities individuals make in understanding their experiences. People are always engaged in making sense of their world, and the individual and the world are therefore mutually-constitutive. By talking to people about their experiences, their relatedness to the world can be understood by examining the meanings they make. These perspectives are unique to the individual's "embodied and situated relationship to the world" (Smith et al., 2009, p.21).

The second major theoretical underpinning of IPA is hermeneutics which is the theory of interpretation. In concurrence with the phenomenological philosopher Heidegger, IPA considers that the meanings of experience are not transparently available but are obtained through interpretive endeavour. IPA researchers are engaged in a double hermeneutic since the researcher and participant are both interpreting. The researcher is making sense of the respondent's attempts to make sense of their experiences (Smith et al., 2009).

IPA is also idiographic in that it is concerned with the detailed examination of an individual participant and their personal perspective. An idiographic approach is amenable to its commitment to phenomenology since it attempts to do justice to the uniquely embodied, situated and perspectival experience of individuals (Smith et al., 2009). IPA therefore employs a small number of purposively-selected participants situated in similar contexts. In line with this idiographic sensibility, narrative accounts of analyses include detailed extracts from individual participants' accounts (Smith & Osborn, 2007). Through examining in great detail how a phenomenon has been understood by particular people in a particular context, meaning and commonality are sought beyond the individual perspective, and general claims can be cautiously developed.

IPA has been used to explore a wide range of issues relevant to health including perceptions of vulnerability to heart disease (Senior et al., 2002), the exploration of grief as a parental response to adult children with schizophrenia (Osborne & Coyle, 2002), understanding why negative genetic test results fail to reassure (Michie, Smith, Senior, & Marteau, 2003), and exploring the role of self and identity in addiction and recovery (Larkin & Griffiths, 2002). Its wide usage has been attributed to its success in balancing complexity and prescription, with accessibility and complexity (Todorova, 2011).

9.4 Validity

Many guidelines and check-lists for determining the validity of qualitative research exist. However, some are arguably too simplistic and prescriptive to capture the nuances of good qualitative work (Smith et al., 2009). Guidelines produced by Yardley (2000) are deemed to be amenable to IPA due to their open-ended, flexible principles (Smith et al., 2009). The four core principles are sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. Smith and colleagues (2009) argue that IPA conforms with all of these principles in a number of different ways. Firstly, IPA is by nature sensitive to context due to its engagement with the idiographic and the particular. The interviewer gauges the interview process so as to adapt to the individual. In addition, analyses are grounded in participants' transcripts to support the interpretations made and to allow the reader to assess their validity. Commitment is demonstrated through the rigour by which the analysis is conducted.

The third principle of transparency and coherence is met by careful descriptions of every stage of the interview and analysis process. Transparency is enhanced by describing in detail the how 1) participants were selected, 2) the interview schedule was developed, 3) the interview was conducted, and 4) the analysis was performed. Yardley's final principle of impact and importance refers to the need for the research to say something useful and important about the research topic. It is argued that IPA researchers aspire to do this (Smith et al., 2009), but ultimately this principle will be determined by the reader.

9.5 Sampling

Participants were purposively selected and this is theoretically consistent with qualitative research and IPA in particular. The study aims to understand the particular perspective of participants with persistent chest pain with normal cardiac test results, and to analyse patterns of similarities and differences within this group. The participants were fairly homogenous in that they continued to experience chest

pain, they had undergone the same procedure of exercise stress testing, and they were all interviewed at approximately one year after testing. This homogeneity enables the examination of psychological variability within the group and transferability to people in similar contexts (Smith et al., 2009). While all participants had persistent chest pain, they had varying levels of prospective health service use in order to explore the varying responses to managing chest pain. Six participants were recruited, which is a recommended number of participants for IPA studies (Smith et al., 2009). The sample size for IPA studies is dependent on the richness of individual experiences, and not the quantity. A concentrated focus on a small number of cases is thus recommended, due to the commitment to the case study level of analysis (Smith, 2011; Smith et al., 2009). Some IPA studies have employed just one participant (e.g. de Visser & Smith, 2006), while six participants is a common sample size (e.g. Chapman, Parameshwar, Jenkins, Large, & Tsui, 2007).

IPA sampling tends to be purposive and broadly homogenous as a small sample size can provide a sufficient perspective given adequate contextualisation (Smith & Osborn, 2003). In this respect, IPA differs from other methodologies, such as grounded theory, as in IPA the aim is to select participants in order to illuminate a particular research question, and to develop a full and interesting interpretation of the data. Grounded theory, on the other hand, uses theoretical sampling, which aims to continue collecting data in the light of the analysis that has already taken place, until no new themes are emerging. Thus, while grounded theory seeks to establish claims for the broader population, IPA studies tend to be more concerned with examining divergence and convergence in smaller samples (Brocki & Wearden, 2006).

9.6 Semi-structured interviewing

Semi-structured interviewing was chosen as the optimal data collection method as it facilitates the collection of first-person, detailed, rich accounts of experiences (Smith et al., 2009). It is thus the data collection method of choice for the vast

majority of IPA researchers (Brocki & Wearden, 2006). The one-to-one interview, in contrast to focus groups, offers participants the space to think and be heard without competition. Unlike structured interviews, semi-structured interviews give participants the opportunity to develop ideas and to speak freely and reflectively. The interviewer can adapt their line of questioning in the light of the responses of participants and explore interesting areas that were unanticipated. Semi-structured interviews are therefore more likely to garner the rich, perspectival data needed for IPA (Smith et al., 2009).

9.7 Interview Schedule

In developing the interview schedule (see Appendix O), the research questions were carefully considered so as to ensure that the set of interview questions would provide opportunities to answer these questions. Seven, open-ended, non-leading questions were developed and put in an appropriate sequence. The schedule began with a straightforward question of describing the chest pain. It was envisioned that participants would feel comfortable talking about this at some length. In order to obtain an insight into the impact of encounters with the health services on participants' understandings of their chest pain, a general question on their experiences with the health services was asked. Participants were not asked about the cause of their pain until towards the end of the interview as a defensive or non-reflective response may have been elicited. Prompts for each question were also prepared to offer participants more concrete questions if needed.

9.8 Interview process

9.8.1 Briefing the participant

Participants were telephoned a few days prior to their interview to prepare them for the interview process. They were reminded of the time commitment and the need for privacy, while the informal nature of the interview was emphasised (Smith et al., 2009). Before interviewing commenced, the interviewer attempted to

establish rapport with the participants by thanking them for agreeing to be interviewed, and by introducing the study and the interview process. Participants were told that the aim of the interview was to learn more about their personal experiences of chest pain and their interactions with health services. It was emphasised that there were no right or wrong answers and they were encouraged to talk as widely and freely as possible about their particular concerns and experiences. They were informed that the interview would last approximately an hour and their permission for the use of a digital recording device was sought. It was explained that the purpose of recording was for interview transcription and they were assured that this would only be heard by the interviewer. They were then informed of how the information they gave would be used. It was explained that a thesis and journal articles would be written based on insights gathered from participants and that quotes might be used. They were guaranteed that names and any other identifying information would be changed so that their identity would be completely anonymous. Their right to stop the interview at any stage and to avoid questions which made them uncomfortable was emphasised. Any questions they had were answered before proceeding with the interview.

9.8.2 Conducting the interview

The interview schedule guided the interview but was used flexibly, and particular concerns and topics which emerged that were beyond the scope of the schedule were explored. From the outset, participants were allowed space and time for their answers to develop, and prompts were used where necessary to help obtain depth and clarity. The line of questioning was generated by attending carefully to the participants' responses. Questions did not test hypotheses nor attempt to corroborate opinions, but were constructed so as to explore the participants' experiences and the meaning attached to these experiences. The interviewer attempted to uncover the 'inner voice' of the participant. The interviews lasted a median of one hour and eighteen minutes. Figure 9.1 below summarises the guidelines followed throughout the interview process for questions and prompts, and the techniques which were employed. These guidelines were compiled from a number of sources which gave recommendations for the interview process that

were consistent with the IPA approach (Kvale & Brinkmann, 2009; Rubin & Rubin, 2005; Seidman, 1991; Smith et al., 2009).

➢ **Questions**

- Use neutral, open-ended, clear & single questions
- Use descriptive, narrative, evaluative & comparative questions
- Avoid "why?" questions
- Avoid over-empathic, manipulative, leading or closed questions
- Ask for concrete details before exploring attitudes and opinions
- Ask to reconstruct the details of a particular experience
- Avoid asking to rely on memory, instead ask: "what was ... like?"
- Wait until participant naturally comes to end of turn before questioning

➢ **Probes/Follow-up questions**

- Repeat, nod or pause
- Invite description & narration
- Prompt examples:
  "can you tell me a bit more about that?"; "what was that like for you?"
- Probe examples:
  "what do you mean by ...?"; "tell me more about this"; "any further examples?"
- Summarise or rephrase for clarification
- If certain words are interesting, ask for elucidation
- Trust instinct if want to hear more about what a participant is saying

➢ **Techniques**

- Use schedule in a flexible manner
- Listen more, talk less.
- Explore laughter
- Tolerate silence
- Err on the side of formality rather than familiarity
- Respect the level of intimacy the participant is willing to share
- Maintain continuity – don't jump to a disconnected topic
- Keep participants focused on the subject of the interview
- Be alert to interview dynamics and adjust line of questioning as necessary
- Suspend or defer rationalisation and evaluation to end
- Show empathy but avoid strong emotional reactions
- Avoid either positively or negatively reinforcing what participant is saying
- Monitor the comfort of the participant and adjust the line of questioning as appropriate
- If participant cries - best to do nothing - let participant work out the distress without interfering. If distress continues, pull back from whatever is causing it.
- Avoid a therapeutic relationship

Figure 9.1 Questions & techniques for interviewing

9.8.3 Debriefing

Once the interview was complete, participants were invited to add anything which they felt had not been covered in the interview, and asked whether they wished to discuss anything further. An opportunity to ask questions about the study was also given. It was ensured that the participants had the interviewer's contact details in case they wished to ask any further questions at a later time.

9.9 Analysis

9.9.1 Transcription

All interviews were transcribed using the Digital Voice Editor supplied with the Sony IC Recorder used for recording. These verbatim transcripts served as the raw data for the analysis. Notable non-verbal utterances such as laughter and big gestures were noted in bracketed text in capitals in the transcript. The transcription of other non-verbal utterances was not required due to the focus of IPA on the content of participants' responses. An explanation of common transcription symbols are displayed in Figure 9.2.

A:	Voice of respondent
I:	Voice of interviewer
-	Break in phrasing
...	Long pause
[ACTION]	Description of action
[LAUGH]	Occurrence of laughter
[ ]	Overlapping voices
/	New idea without pause

Figure 9.2 Transcription symbols

9.9.2 Working with transcripts

The data were analysed according to the IPA analysis guidelines developed by Smith et al. (2009) and Smith and Osborn (2008). This involved an inductive and iterative six-stage process which gradually moved from an initial detailed analysis of

individual transcripts to a more abstracted synthesised account of all the transcripts. Initially, the first transcript was listened to and read repeatedly in order for the analyst to begin the process of becoming absorbed in the participant's world. The process enables the analyst to understand the overall interview structure, to highlight the location of rich extracts, and to note any contradictions or paradoxes.

The second stage of analysis entailed a line-by-line examination of the experiential claims, understandings, and concerns of the participant. Using a hard copy of the transcript with wide margins, the left margin was used to note detailed, comprehensive notes on the description and meaning attached to objects, events, and experiences. This included comments on the semantic content and the use of language to present the content and its meaning. For example, descriptions, idiosyncratic figures of speech, and emotional responses all highlight the meaning of the participant's world. Any similarities, differences, repetition, contradictions, or amplifications within the transcript were noted. These comments had a phenomenological focus in that they stayed close to the participant's explicit meaning. In addition, some preliminary, more interpretative comments were made which helped to understand how and why the subject matter is of concern to the participant. A shift from the descriptive to a more interrogative approach helps make sense of the patterns of meaning within the interview. At the end of this stage, preliminary summaries, associations, and interpretations of the transcript were made. The process is illustrated in Figure 9.3 below which contains a short extract from one of the interviews.

Disappointment Don't want something to be wrong Wants answer Not in your head Feels like moaning Not legitimate to speak about Futility of speaking about it Gets on with it Woman at work getting flutters Woman won't stop talking about her flutters Comical to speak about it Contrasting herself Disapproving of speaking? Wouldn't draw attention to them Woman dramatises her symptoms	A: So that is disappointing now / yeah – it's not that you want to have something – wrong with you / it's just an answer I: [Yeah A: You know] you just feel – it's always not in your head / it's not like you – you're just moaning or you're just – you know – you know you're – that's what I say you don't bother even saying it now like I just - completely get on with it like – you know like / that's / like the woman I work with at the moment she's having these - flutters – like that / she hasn't stopped talking about it [LAUGH] I: [LAUGH] A: And I was like you know – I wouldn't say it you know I: Yeah A: I wouldn't be going around saying now – [BIG INTAKE OF BREATH] – I have them – you know like

Figure 9.3 Example of preliminary coding of data

The third stage of the analytic process is the translation of initial notes into emerging themes. The right margin was used to document concise phrases which captured the essential quality of the participant's voice at a higher level of abstraction. This is a synergistic process of description and interpretation. The themes are "expressed as phrases which speak to the psychological essence of the piece and contain enough particularity to be grounded and enough abstraction to be conceptual" (Smith et al., 2009, p.92). They synthesised the coding at stage two but also adopted a more interrogative stance. The amount of themes generated reflected the richness of the particular extract (Smith & Osborn, 2007). An example of this phase of the analysis is demonstrated in Figure 9.4 using the same extract as above.

A: So that is disappointing now / yeah - it's not that you want to have something – wrong with you / it's just an answer	Disappointment (contradiction) Conflict: Desire to be well vs. desire for answer
I: [Yeah	
A: You know] you just feel – it's always not in your head / it's not like you – you're just moaning or you're just – you know – you know you're – that's what I say you don't bother even saying it now like I just - completely get on with it like – you know like / that's / like the woman I work with at the moment she's having these - flutters – like that she hasn't stopped talking about it [LAUGH]	Need for validation Moaning without legitimate medical complaint Avoiding perceived judgement by keeping silent Disapproving of colleague who discusses her palpitations
I: [LAUGH]	
A: And I was like you know – I wouldn't say it you know	Silence
I: Yeah	
A: I wouldn't be going around saying now – [BIG INTAKE OF BREATH] – I have them – you know like	Dramatising of symptoms comical

Figure 9.4 Example of interpretative coding of data

9.9.3 Developing themes

Once the themes were developed and compiled, the next stage of analysis entailed the clustering of related themes and the development of a structure to the themes to capture the essence of the analyst's reading of the transcript. Some themes clustered together and others emerged as superordinate themes, which helped to draw related themes together. Some themes were discarded in this process and themes which pointed to the most interesting and important aspects of the world of the participant were retained. This process involved numerous techniques including identifying patterns between themes, examining oppositional relationships between themes, identifying contextual elements within the analysis, inspecting repetition of themes, and considering the function of themes within the transcript. A final list of superordinate and constituent themes that most strongly

captured the respondent's concerns emerged with clear traceability to their occurrence in the text.

The process described above was repeated with each of the other transcripts in the fifth stage of the analysis. This rigorous, systematic approach was applied to each transcript on its own terms in order to discern repeating patterns and allow new themes to emerge (see Appendix P). The sixth and final stage involved compiling the themes from each of the transcripts and identifying cumulative patterns across transcripts. A clustering of themes across transcripts then took place and superordinate themes emerged that captured the most important aspects of the participants' shared experience. This was a creative process and involved navigating relationships between convergence and divergence, and between commonality and individuality. Discerning themes particular to unique cases and themes with shared higher order qualities enabled the analysis to progress to a more theoretical level. The superordinate themes which emerged served to describe the most important aspects of experience of the group as a whole. The transcripts were re-visited to ensure that the superordinate themes were significantly present in each account, and to verify the interpretation of the transcripts against the local text itself. At the end of this systematic, iterative process, a table of superordinate themes and their constituent themes was constructed (see Table 9.2).

9.10 Participants

The participants represent a purposive sample, selected for the persistence of their chest pain symptoms. All interviewees had indicated willingness to partake in an interview at the phase of recruitment for the prospective cohort study. Two participants who were invited to an interview declined to partake. Details on the interviewees are displayed in Table 9.1. A balance of males and females was sought, in addition to a variety of health service usage during the follow-up period. As can be seen from the table, four participants were persistent health service users.

Table 9.1 Participants

Anonymised Name (Participant No)	Age	CP Frequency	CP Severity	Persistent HSU
Mark (71)	42	once a month	severe	Yes
Brian (130)	71	daily	moderate	Yes
John (132)	24	once a week	mild	No
Alison (136)	45	once a week	mild	Yes
Laura (308)	37	less than once a month	moderate	No
Kate (314)	43	Several times a week	mild	Yes

9.11 Results

Table 9.2 Themes and sub-themes

Super-ordinate theme	Sub-themes	Indicative quote
Disempowerment of normal test results	Unworthy of care	Brian: "I'd say – Jesus – like there's people - at death's door like – what are you taking up my time for"
	Silence due to perceived insignificance	Laura: "Definitely – you know cos I mean you just – that's when you'd shut up and say nothing / you don't want to [ ] talk about it and just have you know – there's no point – just get on with it really – that's it"
	Hopelessness & negative emotional impact	Brian: "where do you go from here"
	Search for empowerment	John: "she made me / it made me feel better after going to see her – she saying that it was okay like you just want someone to tell you and all okay and what you can do about"
Limbo - Inner struggle of negating & relating to potential causes	Rumination over cause and reality	Kate: "am I imagining this you know – is it is it really / have I really got a chest pain / am I really you know – you start kind of – doubting yourself then"
	Relating to offered or supposed explanations	Kate: "I know – chest and heart might – mine's slightly different or whatever there can be different problems there – but when I think of my chest I think of the heart - you know"
	Accepting or negating psychological attributions	Alison: "I take it easy I / like I'll accept it when they say well this is anxiety / doctor say to you anxiety whereas if I hadn't have read that book I was / there's no way would I have accepted it"
	Techniques for coping and acceptance	John: "I think – I'm used to it now like I can – not that I can control it but I – I can control my emotions more [ ] to deal with it [ ] you know that's why I stop and take a deep breath cos – I know it will go away"
Inadequacy of healthcare to validate & care for symptoms	Validation & need for validation	Laura: "well I did always say please god I know I hope there's nothing wrong with me - but [] I want something to be seen to be believed you know – to – to validate"
	Dismissiveness	Alison: "It's got to the stage with me - I don't know if I'm sick or if I have anxiety because [ ] every time I go to the doctor I'm told I have this anxiety – so I don't know when I'm sick"
	Medical care: helpful or futile?	Laura: "where do you go next [ ] you know what do you [ ] you know – no I'd be sick of saying it all over again I think"
	Questioning the adequacy of care	John: "Like if I if I had waited / if I had to wait like – em – three years just for the results – like a lot can happen in a year like eh – [LAUGH] I could have like – I don't know got hit by a car and I never would have find out"

9.11.1 Disempowerment of normal test results

Unworthy of care: All participants conveyed a sense of unworthiness of medical care. Due to the lack of medical evidence for their symptoms, there was a sense of illegitimacy in attending healthcare services. Brian, Laura, Kate and Alison all referenced a feeling of wasting the time of medical staff. Brian invokes the unspoken voice of his general practitioner to demonstrate this sense of unworthiness:

> I'd say – Jesus – like there's people - at death's door like – what are you taking up my time for.

This dramatic statement conveys the perceived lack of entitlement to seeking medical care. The doctor scolds him for using up his time which could have been spent on more worthy cases. He is portrayed as abrupt and dismissive of his symptoms. Brian's comparison of his symptoms to those who are on death's door further demonstrates the perceived irrelevance of his care-seeking behaviour.

Kate also invokes the unspoken voice of hospital staff to demonstrate her sense of unworthiness:

> You don't really matter / there's nothing wrong with your heart.

The perceived dismissiveness and lack of importance is also evident here. She doesn't "matter" and internalises this sense of unworthiness to the extent that she felt embarrassed to call someone for help, let alone a doctor, despite being very distressed by her symptoms. Her help-seeking behaviour was perceived to be invalid. This feeling of unworthiness is also internalised by Laura who refers to a sense of wasting time on three separate occasions throughout the interview. The perceived judgement is clearly conveyed by the manner in which describes her exit from the emergency department once her test results were clear:

> They just chucked me out of the hospital bed like.

Her use of the verb *chucked out* conveys her sense of feeling discarded and irrelevant. Alison describes a similar experience of being turned away from hospital. Despite her desperate plea for help, she was told there was nothing they could do for her and she was dismissed. Mark and John also both reference a lack of entitlement to medical care for their symptoms. John ridicules himself for seeking help, calling himself an "eejit,"[3] while Mark's reluctance to call an ambulance demonstrates his feeling of unworthiness:

> I've an awful fear of calling an ambulance – I'll be taking it from someone that's seriously ill [ ] and needs it.

Mark questions his worthiness of an ambulance and expresses a sense of guilt that his medical attention will detract from a worthier patient's care. He therefore attempts to reach hospital by means of his own transport the majority of time. All participants express a judgment that they are unworthy of medical attention and appear to have internalised this judgement.

Silence due to perceived insignificance: Not only are the participants' symptoms unworthy of medical attention, they are also undeserving of conversation. Although Kate used to discuss her symptoms with family and friends, she now feels they are unworthy of discussion. While the process of medical testing was ongoing it was a legitimate topic of conversation, but the lack of answers has rendered her silent also. John similarly conveys the unworthiness of discussing his symptoms and laughs at the idea of revealing it to others. They have become irrelevant to speak about since their reality appears to have been denied by medical staff. Alison speaks about the futility in speaking about it even to her husband: "there's nothing he can actually do for me." Brian berates himself for complaining about his symptoms:

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[3] An "eejit" is Irish slang for "idiot".

> Like you'd say to yourself what am I complaining about?

He expresses the sense of unworthiness of discussion. However, he does not conceal it from others and justifies his right to speak about it by establishing the significance of his symptoms. He is adamant that there is something wrong with his system that is worthy of exploration, and is keen to uncover the cause.

For Laura, the concealment of her symptoms is a pervasive theme. She continually references her attempts to hide her symptoms from others, including her husband. She expresses the futility in discussing it and a sense of stoicism: "get on with it." However, her silence appears to be mainly motivated by her avoidance of a perceived judgement that her symptoms are in her mind. She questions whether anyone would believe her since she does not have an explanation. The following extract demonstrates her attempt to avoid an attribution to the mind:

> You just feel – it's always not in your head it's not like you – you're just moaning or you're just – you know – you know you're – that's what I say you don't bother even saying it now like I just - completely get on with it like – you know like / that's like / the woman I work with at the moment she's having these - flutters – like that she hasn't stopped talking about it [LAUGH]

Laura perceives herself to be moaning when discussing her symptoms due to the lack of medical validation. She further demonstrates this perception by belittling - through laughter - her colleague who has begun experiencing similar symptoms recently and has been discussing them incessantly. It is evident that she does not perceive discussion of these symptoms to be legitimate.

In contrast to Laura, Mark is satisfied that others do not judge that it is in his head. He is a counter-case in the sense that his silence is not due to the perceived insignificance of his symptoms, but rather to his avoidance of pressure from others to seek help and to his worry over losing his job.

Hopeless and negative emotional impact: Besides Mark and John, the participants express the sense of hopelessness that can be associated with a lack of answers from medical care.

Despite his desire for answers, Brian feels hopeless in his quest and feels as though he has nowhere to turn. This lack of answers causes him great frustration and confusion and the sense of helplessness is demonstrated in the following passage:

> So like - where do you go from here [ ] do you know what I mean – like I can't just – run down to my GP next – tomorrow or whatever and say listen doctor – I want you to do this or I want you to do that – he he'd probably look at me now and – who's the doctor here you or me.

Brian has no authority to demand tests and therefore feels he has nowhere to turn and is rendered helpless. He is unable to empower himself to receive answers.

Alison and Laura also feel as though they have no-where to turn and Laura questions "where do you go next"? Her sense of helplessness is evident and the negative emotional impact extends to disheartenment and feeling abandoned. Kate expresses similar emotional responses of feeling insignificant, unimportant and additionally experiences anger.

Search for empowerment: While normal tests results have disempowered the participants, they have nevertheless sought to empower themselves by seeking information on the cause of their symptoms. For John, waiting for test results was more distressing than the symptoms themselves. He felt a sense of injustice over the delay in imparting the results and needed them in order to ease his mind and cope with his symptoms. The following passage indicates the importance of receiving information:

John: As long as you – as long as you know you can do something about it it's better – than not knowing like she could have said –

Interviewer: Mmmhhh

John: Oh you – you have a defective heart and you need to do this and I was like – oh alright at least I can do something about it

Receiving knowledge empowers the patient to act on it, whether that is knowledge of a heart defect or knowledge that the heart is normal. He equates the sense of relief and empowerment upon hearing both possibilities. In his search for empowerment, he resorted to trying to gauge the reactions of people in the testing rooms for any signs of how he was performing. John feels a lack of ownership over his body and believes he has a right to know what is happening and for increased transparency. When he finally received information on his results, he felt empowered to manage his symptoms.

Laura continually references her desire and need for an explanation. She is constantly searching for an answer yet received none from medical professionals, and therefore feels a sense of isolation. She never even received the results of her exercise stress test and therefore has no sense of closure.

Alison poses a simple yet thought-provoking question:

> So if that was happening to you wouldn't you like to know why it's happening?

It does seem natural to be curious about the cause of distressing symptoms and reasonable to expect to get an answer from medical professionals. She even offered possible explanations to her GP such as a problem with her thyroid, but they were dismissed. It is only through purchasing a cognitive-behavioural programme (CBT) on the internet that she empowered herself to understand her symptoms.

Kate also offered possible explanations to her doctor in her search for understanding but her queries were unanswered. When she suggested it could be

caused by her weight she was told it was possible but was provided with no further feedback. Despite a desire for more information, she feels unable to ask her doctor for an explanation.

Mark was initially offered no explanation but on his third visit to the emergency department, in contrast to Kate, he demanded an answer and received an explanation of muscle spasms. Brian also showed no hesitation in posing questions to his doctor. He uses the analogy of his car breaking down to justify his search for information:

> I've a car – and if I went out this morning and that car didn't start – or even if it started and it was stuttering I'd be saying – I better go and see a mechanic [ ] I don't want to I don't want to find myself – out in the middle of nowhere – having to ring for – assistance like you know.

9.11.2 Limbo – Inner struggle of negating and relating to potential causes

Rumination over cause and reality: All the participants question the cause of their symptoms and some even their very reality. John speaks about the constant questioning of his symptoms. He questions whether it was in his head, whether perhaps he's "just like a regular person" and it is a normal process, or whether it's his heart. The process of waiting for test results intensified the uncertainty and caused incessant worry. He had to live with the possibility of having a heart defect:

> But like if you've got something wrong with your heart – it's a big thing - eh [LAUGH] so – everybody was trying to put my mind at ease saying ah you know – there's like loads of things they can do with your heart now or whatever.

The very act of testing the heart calls into question the functioning of the heart, which John maintains is inevitably worrying. He therefore had to live with the potential of having a heart problem and the potential interventions in the future.

Ruminating about potential causes was also a predominant theme for Kate. Possible causes such as panic, smoking, post-natal depression, and weight were all considered. The very reality of the symptoms was also questioned:

> Am I imagining this you know – is it / is it really / have I really got a chest pain / am I really you know – you start kind of – doubting yourself then.

She questioned whether her symptoms were imagined due to the confusion in making sense of them. Other unresolved questions also filled her mind such as will it get worse or will she cope? She describes this confusion and uncertainty as "limbo". Laura and Alison are similarly stuck in limbo and uncontrollably question the cause of symptoms. The sense of despair of this uncertainty is captured by Alison:

> I haven't got a clue ... I just haven't got a clue ... just the feelings and the sensations that goes through my body – is like .... they would literally drive you insane.

Brian and Mark also struggle to make sense of the cause of their symptoms. Mark questions the potential causes of his symptoms and rules out possibilities in his head. His uncertainty remains until he hears his test results:

> I do have butterflies – in my stomach – when he comes back and tells me well - will I have this or will I have it's just like [ ] if they come back and tell me that it's all clear I just jump and say – jump up and shake their hand and hug them.

The nervousness and use of the word "if" indicates the doubt and uncertainty he has over the outcome of his results.

Relating to offered or supposed explanations: A wide range of explanations for symptoms are proposed by the participants, some of which have been offered by medical professionals and others which have come from their own reasoning.

Although Kate was not offered an explanation from her doctors, she was able to relate to her mothers suggestion of anxiety as a contributor. Her mother saw a relationship between her symptoms and her brother's panic attacks, and Kate was able to decipher the connection also once it was suggested to her. Her symptoms then began to make sense:

> And then as I kind of put – things together I thought it was – to do with anxiety it must be.

With the benefit of hindsight, she could see that anxiety definitely contributed to her symptoms although she didn't realise she was anxious at the time. She had automatically associated her chest pain with her heart, but has re-attributed the sensations to anxiety and to perhaps being over-weight.

Mark appears to be accepting of the medical attribution of muscular pain to his symptoms. Although he questions the possibility of other causes, this explanation appears to fit due to his heavy physical labour at work:

> But – I sit down and think about it – it couldn't be that and it couldn't be that / it couldn't be this – so it had to be this – but me pushing the eleven hundred bins when they're full.

Mark relates to this explanation of muscular pain and internalises it: "I put it down to muscles." John also relates to the explanation offered during cardiology clinic visits. The offered explanations of the lifestyle triggers of stress, being run down, and drinking sweeteners or alcohol made sense to him and he was therefore reassured. He is now able to "put two and two together" and attribute his symptoms to a lifestyle cause.

Alison immediately related to the symptoms described in the cognitive-behavioural therapy self-help book she purchased from the internet and therefore was able to

accept anxiety as an explanation for her symptoms. Laura has a tougher time relating to an explanation since she has not been offered a viable alternative to the heart. She therefore continues to question lots of possibilities and struggles to dismiss them from her mind. For example, she attributed her symptoms to low B12 levels when her deficiency in B12 was discovered in a blood test. Once her B12 levels returned to normal however, she struggled to find an alternative explanation:

Laura:	My B12 is low I know it is like it has to be that – and it was perfect so – again that was like god / it's not my B12 you know
Interviewer:	[Mmm
Laura:	Then I] saying would it be thyroid or something / that was all checked I had it all checked and –
Interviewer:	Okay
Laura:	Perfect – you know – everything / cholesterol / everything perfect you know – so this time – this year my B12 was perfect for the first time it's actually kind of perfect - whereas before it was always – you know – low I would be low and I'd always – I'm getting more from / that's it - it's my B12.

Although one would expect a normal test result to induce a feeling of relief, she is clearly shocked that her B12 has returned to normal. The disconnected language indicates this confusion. Laura is now left with no attribution for her symptoms, which she so evidently desires.

Brian is unique in that he attributes his symptoms to the aftermath and complications of a colonoscopy exam. Although on the surface it seems like a highly unusual attribution, there are a number of factors which illuminate his thought process. Firstly, he experienced a lot of pain during his test and secondly, his doctor spotted something he wanted to investigate further and requested that he be monitored with a colonoscopy examination on a yearly basis. Although Brian was not given any information on whether there was cause for concern, he detected a sense of urgency from the doctor which frightened him. He therefore questions whether it is possible that damage was done during the colonoscopy which could

have onset his symptoms, or whether there was something untoward detected which he has not been informed of. The colonoscopy test is the only test which he perceives to have shown some abnormality, and an abnormal test result offers a valid, medical explanation for his symptoms:

> But as I say that's how the echocardiogram came about – and – it showed up nothing – the x-rays / chest x-rays showed up nothing – the only one that – showed – as far as I can see – was the colonoscopy.

Although he is struggling to make sense of this explanation and it is not corroborated by his doctors despite attempts to do so, it is the only valid explanation he can relate to.

Accepting or negating psychological attributions: The extent to which the participants accepted a psychological attribution to their symptoms varied considerably. While John, Kate and Alison were accepting of it, the others negated a psychological attribution.

Mark's negation of a psychological attribution is not very substantial since he felt reassured by his doctor that it wasn't a psychological problem. In stark contrast, Laura is very defensive and annoyed about a potential attribution to depression or stress, and works throughout the interview to negate this attribution. She uses a number of techniques to achieve this. She presents herself as a calm, happy person and normalises her level of stress. The perceived judgement of a psychological attribution threatens this sense of identity and she therefore works to maintain it. Laura is so attuned to the judgement of depression, she was reluctant to fill out the questionnaire for this study as she feared being labelled depressed.

> As I read through even when you read the - thing I said ah – I'm not depressed like [LAUGH] you know I'm not depressed – you know.

The above text highlights her defensiveness at the suggestion of depression. Laura does not consider stress or depression to be legitimate explanations for pain and repeatedly refers to the association of that attribution to a judgement that the pain is imagined. She therefore vehemently opposes this perception.

Brian is an unusual case in that although he is accepting of medication for anxiety and depression, he is not accepting of anxiety or depression as potential causes of his symptoms:

Brian:	Do you know what I mean – like my own my own doctor said it it looks like anxiety – but I think myself – if your system is not right – if it's bound to have a bearing on the way you feel and the way you think
Interviewer:	Mmm
Brian:	You know what I mean - that's not to say there's something wrong – but something has to be wrong.

Brian does not appear to concur with his doctor's opinion that his symptoms are caused by anxiety. He speaks to the inevitability of anxiety when the body is "not right". While he acknowledges that anxiety does not necessarily mean there is something wrong with the body, in his case he seems fairly certain that there is something physically wrong. He is accepting that he has symptoms of anxiety and therefore acknowledges that the medication helped him to gain weight. However, an attribution to anxiety is a different matter. He flippantly remarks "whatever" in relation to this attribution, indicating his dismissiveness of this explanation.

On the other hand, Kate and John are accepting of a psychological attribution. Kate is aware that her symptoms are preceded by worry and John has a similar insight into the link between worry and symptoms. He also has insight that he might not be aware that he is stressed, and about the potential for a delayed reaction of stress on the body. He can therefore understand why he may not experience symptoms until he is attempting to relax. This is in contrast to Laura and Brian who were confused by the occurrence during relaxation periods. Symptoms did not occur

during stressful times during the day, but when in a relaxed state. Laura struggles to understand this: "I always seem to get them when I'm most relaxed - that's the funny thing about it". In Laura's case, her tendency to be relaxing when experiencing symptoms was used as an argument against a stress attribution.

Alison attributes her chest pain to panic and stress and understands the physical reaction of the body to stress. She was only able to relate to this explanation due to her purchase of a cognitive-behavioural programme on the internet. Reading this book enabled her to accept an explanation of anxiety. And although she acknowledges the validity of the attribution to anxiety, it is important for her to distinguish anxiety from mental illness. She appears keen not to be labelled as mentally ill and went to great lengths to prevent this perception:

> I had a terrible fear of ending up looking like these people [ ] I have to go out and I'd have to buy new clothes and I'd make sure my makeup was on perfect and my hair was perfect"

She distances herself from being mentally ill by referring to "these" people and her effort into appearance served to avoid the stigma of looking like "them."

Techniques for coping and acceptance: All the participants demonstrate techniques to accept their symptoms, the most common being the downplaying of symptoms and self-soothing inner dialogue. Other techniques include belittling symptoms, distraction, breathing, oppressing thoughts, and normalising symptoms.

Mark primarily copes through the use of pain medication, but also consoles himself with positive thinking and uses distraction techniques. Brian uses walking as a coping mechanism and also downplays the significance of his symptoms. John is more resourceful and uses a variety of techniques including deep breathing to clear his mind, belittling his symptoms, oppressing thoughts of potential causes, and normalising it as "just another thing." He is keen to portray his symptoms as a

forgotten issue. John attributes his previous inability to accept the uncertainty of his symptoms as immaturity.

> And now I know that – stop asking questions or stop – I'm more mature – cos I'm – just older now and – I know – stuff like it happens and you just have to get on with it.

He berates his incessant worry as an immature response and scolds himself for worrying. Laura is similarly resourceful and uses the same techniques of breathing, belittling her symptoms, oppressing thoughts, normalising them as "a feeling", and scolding her uncertainty, in addition to the use of self-soothing inner dialogue. For example, she reassured herself that her testing had been comprehensive. Her description of her symptoms as "a feeling" indicates a normalisation of the sensations she is experiencing:

> And that's / all I put it down to now is a feeling / like a feeling like butterflies in your stomach.

A "feeling" is a perfectly normal physical process and "butterflies" are a normal and common reaction to anxiety. By normalising the sensations, it enables her to accept them.

Alison's primary techniques for coping are distraction and self-soothing inner dialogue. The following extract demonstrates both these techniques at work:

> I'm talking to myself in the car right [ ] do not let this get to you – you're fine – this has happened to you before [ ] take your mind off it – one two three four five six seven eight nine [LAUGH].

The counting helps to distract her and her self-soothing dialogue consoles herself that the symptoms will pass and assures herself that she can cope.

Kate employs all the aforementioned techniques. She dismisses it as "just something that happens," distracts herself through music and conversing with friends, and she continually self-soothes herself with inner dialogue such as her symptoms are not harmful.

9.11.3 Inadequacy of healthcare to validate and care for symptoms

Validation and need for validation: The sense that symptoms have been invalidated or the need for validation is expressed by all participants except for Mark. Symptoms are invalidated in the sense that they are dismissed as "nothing". John has internalised this lack of validation which is evident by his statement "it's not like I have an ailment".

Kate, Brian, Laura and Alison all appear to desire for a test to show some abnormality in order to validate their symptoms. The receipt of normal test results has a bitter-sweet taste. On the one hand, Kate feels a sense of relief that her heart is okay but, on the other hand, it leaves the question of the cause of her symptoms unanswered.

> I was delighted of course – but / I was kind of – what is it then you know.

This conflict is present due to the perceived validation of abnormal test results. Despite feeling happy that nothing was seriously wrong, the lack of answers was distressing. This conflict is also experienced by Brian. He is willing to pay a lot of money for a test if it meant it would provide him with an answer.

> I often think to myself – if it cost me a grand – it would be a grand well spent – if you went to somebody that could actually – do a test and could turn around to say to you – I know what the problem is.

The desire for answers appears to override the desire to be well. The focus of all the interviews was not on the desire to be well but on the desire for an explanation. Alison was hopeful that the echocardiogram would be the test that would show

some abnormality and that hope enabled her to cope with her symptoms while waiting for her test. Laura explicitly expressed the perceived validation of an abnormal test:

> Well I did always say please god I know I hope there's nothing wrong with me - but [ ] I want something to be seen to be believed you know – to – to validate

Again the desire for answers overrides all other concerns. An abnormal test enables a sense of feeling believed and authenticates the symptom. Laura also reveals how the end to testing denotes the end to validation.

> In the beginning when you're – getting all this attention that you're getting seen to and you're – you know – it's like – that's not in my head thank god [ ] that's not in my head – and then – it's like – it just stops at that there and then – it's just I think really / not getting any – any follow up / really now – disheartened me completely.

The process of hospital procedures legitimised the complaint and validated it as real as opposed to "in [the] head." Once testing has ceased however, an abrupt withdrawal of the validation occurred. Laura then felt that she was "not believed" and that the reality of the symptoms had been denied.

Dismissiveness: The dismissiveness of medical professionals was felt in varying degrees by the participants. Mark did not experience feeling dismissed. He claimed that his GP often sends him to the emergency department for her own reassurance and not just for his. His chest pain seems to be taken seriously. On the other hand, John felt dismissed after testing in the sense that no information was provided and he was simply told "goodbye." The remaining participants all felt dismissed at a deeper level. Since no defect could be found with their hearts, they were dismissed from medical care. Laura captures this well:

> I think at the hospital that time when everything was all clear - and everything was okay it was like / you're discharged now goodbye - and that was it – you know and [ ]

> Jesus Christ there's nothing like / you're just – doing a test and you're back / it's after coming back okay so it's obviously go / goodbye and that's it.

"Goodbye" conveys a sense of coldness and detachment on the part of medical staff. Due to a lack of positive test results, she becomes a closed case and no further help is warranted. A further demonstration of dismissiveness is the prescribing of medication by her GP. When she sought an explanation for the cause from her GP, she was prescribed medication to "see how it goes," which she perceived as avoiding an explanation. Brian also speaks about the dismissive nature of prescribing medication. In addition, he voices his frustration with the lack of attention to invisible symptoms:

> If they can't see it then how are they going to deal with it [ ] maybe I'd have to / if I collapse on the floor and come in a stretcher and they brought me in / in an ambulance maybe then maybe they'd say well – we need to look at this and we need to look at that / or whatever I don't know.

Brian defends the dismissiveness of doctors since they are unable to offer assistance to symptoms that are invisible. Nevertheless, he shows his desperation to be paid attention to by suggesting his need to collapse in order for his symptoms to be taken seriously. Alison similarly conveys the perceived inadequacy of dismissing unexplainable symptoms. However, a more worrying aspect is the attribution of all other symptoms to anxiety:

> It's got to the stage with me - I don't know if I'm sick or if I have anxiety because [ ] every time I go to the doctor I'm told I have this anxiety – so I don't know when I'm sick.

Alison has been branded as anxious and she perceives that all her symptoms are dismissed as such. The potential for validated sickness has been denied.

Medical care: helpful or futile? Both Kate and John neither speak about the futility nor helpfulness of healthcare-seeking behaviour since they appear to have accepted their symptoms, and do not perceive a need for any further help. For Mark however, attending hospital offers a legitimate way of leaving work. The pressure to remain at work is acute for Mark and he has a great fear of losing his job over his symptoms. Mark suffers with intense pain on a daily basis which greatly affects his work. This causes tension with his boss which eases when he informs him he is going to hospital. Mark also justifies his need for attending hospital due to the unbearable nature of his pain:

> But when it's very severe you just think – enough – get me an ambulance – can't get up – left for dead.

When the pain becomes unbearable, he sees no other alternative but to call an ambulance. Mark dramatises the nature of his pain by stating he is "left for dead," which serves to justify his need for medical care.

In contrast to Mark - Brian, Laura, and Alison all refer to the futility of medical care. Brian considers he has exhausted all potential services available to him and now has nowhere to turn:

> I've had loads of tests / well I think I have anyway – like from CAT scans / echocardiograms / kidney x-rays – chest x-rays em – colonoscopies so like – what else is there to do.

He demonstrates his sense of hopelessness and futility in seeking further care. Laura similarly struggles with the point in future care seeking. She presumes inaction but also speaks about the lack of progress in the testing process:

> You know like cos - you're not progressing to anything / you're not getting an answer – you know what I mean / in the beginning you're going / you're going for your consultant and you're waiting on this test and you're going up – you're getting

> somewhere [ ] you're getting a bit of progress but – when that comes back then you're back down to the end of the ladder – that's the way I feel.

Waiting for tests and appointments offer her a sense of progression in the quest for an explanation, yet when tests are normal, she feels she has taken a step backwards or has sunk "to the end of the ladder." This metaphor conveys her sense of despair and frustration with the medical testing process. She has conceded that an answer is unattainable and that medical care is pointless. Not only does she feel she is wasting doctors' time, but also her own. Throughout the interview, she repetitively speaks of the futility of seeking help. Alison also refers to the futility of seeking help since "there's nothing they can do."

Questioning the adequacy of care: All but Mark question the adequacy of the care they received. Laura considers she received insufficient information and support, and highlights that the nature of the complaint warrants follow-up. Despite seeking advice and reassurance, neither was offered and she alludes to a perceived lack of will on the part of medics to help. "They don't want to do anything else" once the heart as a cause has been ruled out.

Alison similarly highlights that inadequate information was provided and expresses a sense of disbelief over the lack of answers and support. She claims that her deterioration to the point of attempted suicide could have been prevented if assistance had been offered initially at the hospital:

> Someone should have been there – and for them to be able to – for them to deal with me in that hospital instead of having to wait six weeks and lose three stone [ ] and go – to try and kill myself – before I seen somebody in the mental part of it.

She also questions to need to attend mental health hospitals and believes assistance should be offered in local hospitals, particularly cognitive-behavioural therapy (CBT). She questions why CBT is not readily available and the inadequacy of

simply prescribing medication that masks rather than deals with symptoms, and turned her into a "zombie."

Kate claims the answers she received were inadequate and tentatively questions the adequacy of her care also. She questions whether a referral should have been made to find the cause of her symptoms and to enable her manage them.

Although Brian reports positive experiences with his medical care including the comprehensiveness of his testing and his confidence in his GP's judgement, he intersperses the conversation with numerous stories about inadequacy of health professionals. Stories range from making a blunder of taking his blood to the lack of referral of his wife's cancer which ultimately ended in her death. He claims that it is "luck" whether one has a good experience with the medical system and that the best treatment or best specialist is insufficient to guarantee good results.

John also had positive experiences with healthcare. He was given consistent information and had comprehensive testing. In addition, the staff were supportive and reassuring, and follow-up was offered if needed. The only aspect of the adequacy of care which was questioned by John was the waiting times for tests and information, yet this was a substantial problem for him. The following extract demonstrates his sense of frustration with waiting times:

> Like if I if I had waited if I had to wait like – em – three years just for the results – like a lot can happen in a year like eh – [LAUGH] I could have like – I don't know got hit by a car and I never would have find out.

Despite the comical nature of this statement, it nevertheless conveys the inadequacy of waiting times. He particularly expressed disbelief over the waiting time for his echocardiogram, and could not fathom the necessity to wait months before receiving test results. John does not consider a simple phone call unreasonable to expect.

Mark similarly praises the services he has received but in contrast to John, he portrays his lack of frustration with delays. He prides himself in respecting staff and not losing his cool with staff as he has seen others do in the emergency room. However, Mark's perspective is that of an emergency department patient as opposed to an outpatient, whose patient journey differs greatly.

9.12 Summary

The following super-ordinate themes were identified in the analysis: disempowerment of normal test results; limbo – inner struggle of negating and relating to potential causes; and inadequacy of healthcare to validate and care for symptoms. Participants felt disempowered by their lack of abnormal test results and sought to empower themselves by seeking information on the cause of the symptoms. They struggled with making sense of their symptoms by relating to and negating actual and potential attributions. Finally, the inadequacy of medical services to address and care for the symptoms of participants was questioned and the futility of future healthcare-seeking behaviour was considered.

Chapter 10: Discussion

10.1 Introduction

NCCP has not been studied previously in Ireland and thus information for the Irish system is novel. The study has also made a number of unique contributions to the general literature on NCCP. In particular, the importance of cardiac anxiety and gastro-oesophageal and musculoskeletal-like symptoms in predicting outcomes of persistent pain and persistent health service use has been highlighted. In addition, poor communication with patients regarding test results and explanation for their pain has been demonstrated to contribute to poor outcomes. This final chapter summarises the results of both the prospective cohort and qualitative studies. The aim of the cohort study was to examine predictors of persistent chest pain and persistent healthcare utilisation in patients with normal cardiac test results. The qualitative study explored how participants interpreted their chest pain in the context of normal test results. In particular, the impact of interactions with health services on their interpretation of their symptoms was examined. Potential limitations and strengths of the studies are assessed. The results are interpreted in relation to the aims of the study and in light of the existing literature. Implications and recommendations for interventions, practice, and research are then considered.

10.2 Study strengths and limitations

This study has a number of strengths as well as limitations. The primary strength of the study is the prospective design. Most research on NCCP has focused on examining its relationship to physical and psychosocial variables in cross-sectional, observational studies. In order to understand the factors important in the aetiology and maintenance of symptoms, more prospective cohort studies are needed. The chosen outcome variables of continued chest pain and health service use were important for understanding the course of symptoms and service use in this patient

group. In the small number of prospective studies that have been conducted, chosen outcome variables are generally psychological factors such as health-related quality of life or psychological distress (e.g. Bringager, Friis, Arnesen, & Dammen, 2008). Even intervention studies have chosen these variables as their outcomes of interest (e.g. Jonsbu, Dammen, Morken, Moum, & Martinsen, 2011). In order to be able to develop effective interventions, a greater understanding of the variables related to persistent symptoms and service use Is also needed. The relatively long follow-up period of this study enabled an examination of patterns of outcomes which are unlikely to be temporary.

Another strength of the study is the multi-factorial approach, guided by the model developed by Bass and Mayou (2002). While there is a large literature on the association between NCCP and psychological factors, very few studies incorporate both physical and psychosocial variables. Disciplines with an interest in NCCP including gastroenterology, psychology, and psychiatry tend to study this patient group separately. This study adopted a cross-disciplinary approach by examining both physical and psychosocial factors, and also operationalised service-related factors theorised to be important in the literature, but not previously examined (e.g. prior explanation of angina).

The measurement of baseline variables prior to cardiac testing was a further strength. Other studies have administered measures after the receipt of test results (e.g. White et al., 2008). Yet patients' perceptions and levels of cardiac anxiety are likely to be influenced by the receipt of normal cardiac test results. Measurement prior to testing when patients are unaware of the origin of their pain ensured that the testing process did not influence the results of self-report measures.

The use of a mixed methods approach was also valuable in examining this complex symptom. Qualitative analysis of the in-depth semi-structured interviews allowed the access to service-related issues, which are immeasurable by survey methods. The qualitative study enhanced understanding of patient perceptions, attributions,

and healthcare encounters. The dynamic, fluid nature of symptom interpretations was evidenced.

This study had a number of limitations which should be considered when interpreting the findings. Firstly, the sample may not be fully representative of NCCP patients. Participants were recruited from both emergency and outpatient settings, in order to enhance the representativeness of the sample. However, a small number of patients were excluded due to cognitive Impairment (n=6) and inability to communicate in English (n=5). Although those who declined to participate did not differ from participants in terms of the demographic variables of age and sex, other clinical differences may have been present which were not measured. In addition, a very high participation rate of 92% at follow-up was achieved at follow-up, but non-participants appeared to differ on a number of psychological variables. A selection bias towards patients with lower levels of psychological morbidity is therefore possible, but the small number of non-participants (n=11) may mean that the differences are negligible.

A further cautionary note should be made regarding sampling. The recruitment of patients at the point of referral for exercise stress testing excludes patients who were referred directly for angiography. These patients are at a higher risk of CAD, yet nevertheless could have NCCP. There also may be NCCP patients presenting in primary care that are not referred to outpatient cardiology departments. This limits the generalisability of the findings to patients referred for an EST in both emergency and outpatient settings. The care experiences of patients recruited from emergency and outpatient settings differ, however. The qualitative analysis demonstrated the role of experiences with healthcare services in the interpretation of chest pain and healthcare-seeking behaviour. However, this is reflective of routine hospital practice in Ireland. The sampling also adds to the ecological validity of the sample. Studies tend to recruit from one setting such as the emergency department, which is likely to skew findings. It is nevertheless important to interpret the present findings in the context of the particular healthcare setting. However, patient type (outpatient/inpatient) was controlled for in multivariate

analyses so that relationships independent of treatment setting could be ascertained. It is likely that differences with other settings such as chest pain units exist, and further research examining different care settings is warranted.

Another limitation is the potential for unidentified medical aetiologies of chest pain. Some participants may have had undetected CAD or an undetected, serious physical cause. The reliability of exercise stress testing is dependent upon patients' achievement of maximum heart rate which does not always occur. A greater reliability of a non-cardiac diagnosis would have been achieved by recruiting patients referred for coronary angiography. However, low-risk patients would not have been included in the sample. In addition, the aim of this study was not to determine the cause of chest pain, but to examine the experiences of participants with normal cardiac test results, and to investigate the outcomes of these participants. The methodology reflects routine clinical care for this patient group.

The reliance on self-report measures is a further limitation of the study. Diagnostic interviews to establish psychiatric co-morbidity would have been more accurate than self-report measures. Resource constraints did not facilitate this, and furthermore, it would have increased the participation burden, thus possibly reducing the participation rate. Despite the limitation, the psychological scales demonstrated good psychometric properties, and are widely used in this context. The examination of the relationship between baseline variables and future outcomes helped to establish which patients might benefit the most from intervention, as soon as NCCP is detected. However, the measurement of variables at an increased number of time-points during the follow-up period would have enabled examination of the variation in variables over time, and information on how this variation may have impacted on outcomes.

Verification of reported healthcare utilisation would also have increased the reliability of findings. Unfortunately, linked, electronic medical records do not exist for patients in Ireland, and reliance on self-reported usage was therefore necessary. Most studies of health service use in NCCP patients have employed self-report

measures (e.g. Eslick & Talley, 2004b; White et al., 2008). Self-reported health service utilisation has been demonstrated to concord well with registers. For example, one study examining self-reported and registered hospitalisation in 1,277 cases found that the percentage of accurately reported hospitalisation was 96% and a kappa of 0.80 was reported (Reijneveld & Stronks, 2001). Nevertheless, the agreement has been shown to vary according to cognitive abilities, type of utilisation, and recall time frame, for example (Bhandari & Wagner, 2006), and the potential for over-estimation and/or under-estimation thus exists. The lack of medical record linkage may further facilitate healthcare utilisation, since participants can attend an alternative hospital if unsatisfied with the care received at another. Anecdotally, some NCCP patients in Ireland have been known to present to a number of different physicians and hospitals due to lack of satisfaction with healthcare.

Due to the numerous factors implicated in the aetiology and maintenance of NCCP, it is possible that confounding variables were not identified or measured. A balance between the inclusion of all relevant variables in the model proposed by Bass and Mayou (2002) which guided the research, and questionnaire burden and acceptability was sought. Other variables such as stress, personality, and general health anxiety were considered, but high correlations with the existing variables in the study were expected. Variables that were examined also had high correlations, making the development of multivariate models difficult. The small participant numbers, particularly for the multinomial regression analyses, also limited the ability to perform multivariate modelling. Another possible confounder could be co-morbidity of disease, which was not examined. Hence, only health service utilisation for the primary reason of chest pain was evaluated, due to possible service use for co-morbid illnesses or symptoms.

10.3 Prospective cohort study findings in relation to the literature

10.3.1 Demographic variables

One hundred and sixty nine participants were recruited to the study, 86% of whom had normal cardiac test results. Although the proportion of participants with normal test results is higher than studies primarily conducted in emergency settings, it is comparable to a large study on the prevalence of NCCP in primary care (83%) (Glombiewski et al., 2010). The majority of this sample had been referred to EST testing by general practitioners, which may explain the concordance with this study. In addition, high quality epidemiological information on NCCP is lacking and inclusion criteria vary widely, making comparison difficult.

A sample of 145 participants with non-cardiac chest pain was attained and 134 (92%) participated in the one-year follow-up. The baseline age ranged from 18 to 83 years with a mean age of 51 years, which is comparable to demographic data on NCCP patients recruited in the UK (e.g. Dumville et al., 2007). Approximately equal numbers of men and women were recruited, as found in other studies on patients with NCCP (e.g. Leise et al., 2010). The socio-demographic profile of participants appears to be slightly more deprived than the general population, as evidenced by a higher proportion of participants with medical cards (9% more) and a lower proportion with private health insurance (14% less) (Central Statistics Office, 2011).

10.3.2 Baseline variables

10.3.2.1 Chest pain

Approximately one quarter reported chest pain at a frequency of several times a week and just under half experienced it at least weekly. Moderate intensity was the most common severity rating (52%), which was also reported by the majority (41%) of participants in a study of 126 NCCP patients (Eslick & Talley, 2008b). This study reported a lower median symptom frequency (< once per month), however. In the current study, chest pain had begun in the preceding year for approximately half of

the participants, yet a sizeable proportion of 37% had experienced chest pain for more than two years. Symptom commencement is generally not reported in this patient group, disabling comparison to other studies.

10.3.2.2 Physical variables

At baseline, physical symptoms of heartburn and acid regurgitation at a frequency of at least once per month were relatively common. One third (33%) of participants reported heartburn and 26% reported acid regurgitation at this frequency. Dysphagia, or difficulty swallowing, was not as common and was reported by 12%. These levels of gastrointestinal symptoms are lower than found elsewhere. Eslick and Talley (2004b, 2008b) found that 51% reported acid regurgitation, 53% reported heartburn, and 32% reported dysphagia at a frequency of at least once per month. Almost identical levels of pain suggestive of a musculoskeletal origin were found, however. In this study, musculoskeletal-like pain was indicated by a high proportion of 57%, similar to the proportion of 56% found by Eslick and Talley.

10.3.2.3 Emotional variables

High levels of psychological distress were found in the sample. Scores on the HADS (Zigmond & Snaith, 1983) were lower than found in another study of NCCP patients employing the HADS (Eken et al., 2010). In this study, 38% scored 10 or more on the HADS-A, compared to 31% in this sample, and 52% scored 7 or more on the HADS-D, compared to 25% in this sample. The recruitment setting of the emergency department, in comparison to the inclusion of patients from outpatient departments or primary care, may account for these differences. A wide range of psychological morbidity has been detected in NCCP patients, possibly due the wide heterogeneity of studies and NCCP patients. Levels of anxiety, depression, and/or somatisation disorders range from approximately 47-80% (Dammen et al., 2004; Okpa et al., 2003). Further research is needed to discern which patients are more likely to have psychological morbidity, and in which settings.

Little research has previously examined somatisation in NCCP patients. Levels of somatisation in this sample, as measured by the PHQ-15 (Kroenke et al., 2002),

were minimal or low in just over half of participants (54%). However, half (25%) fell within the medium range and 23% demonstrated high levels of somatisation. Similar findings have been found in primary care settings. For example, a study in a German primary care setting found that 23% of participants indicated presence of a somatoform disorder, as measured by the PHQ-15 (Körber et al., 2011). The proportion is also similar to that found in a sample of NCCP patients attending cardiology outpatient clinics (Bringager et al., 2008). Nineteen per cent met criteria for somatisation disorder, which was confirmed in a nine-year follow-up. In a study employing diagnostic psychiatric interviews, a lower proportion of 14% were classified as having somatoform disorders (Jonsbu et al., 2009). This study also reported that 14% met criteria for panic disorder, compared to almost one quarter of participants in this study. A wide range of panic disorder has been detected in this population group however. A review of the literature found that co-morbidity of panic disorder ranged from 11-76% (Maunder, 1998). Varying patient recruitment settings and measures are likely to account for this wide range.

High levels of cardiac anxiety were found among participants at baseline, and the mean score of 28.3 on the Cardiac Anxiety Questionnaire (CAQ) was similar to that found by the constructers of the scale (Eifert & Lau, 2001; Eifert et al., 2000a). In a randomised controlled trial examining the role of cardiac anxiety, mean CAQ scores ranged from 25.7 to 28.9 across the three treatment groups, which was comparable to this study (Spinhoven et al., 2011). Other studies reporting levels of cardiac anxiety have included patients with cardiac disease, thus making direct comparison difficult.

10.3.2.4 Cognitive variables

Illness perceptions as measured by the B-IPQ (Broadbent et al., 2006) varied considerably between participants. Generally, participants perceived low levels of consequences to their illness. However, negative perceptions were also evident. Participants felt a lack of personal control over their symptoms, high levels of concern for their symptoms, and a lack of understanding about their condition. There was a wide variability in perceptions of timeline, identity, and emotional

affect among participants. While some regarded their chest pain as an acute symptom, others believed it would continue into the future. The degree to which participants were emotionally affected by their chest pain also varied considerably, as did their sense of illness identity.

While illness perceptions as measured by the B-IPQ have been previously examined (Donkin et al., 2006), descriptive statistics have not been reported on, and comparison is therefore not possible. Data on attributions in NCCP patients is available, however. Similar mean attributions to a gastrointestinal cause (2.6) and psychological cause (3.2) were found in a previous study (Dammen et al., 2004). Slightly higher mean attributions to a cardiac cause were found in the present study, however (3.4 vs. 2.5). Participants found it difficult to attribute their chest pain and a sizeable proportion (approximately 20%) were unable to rate their attributions, due to uncertainty of cause. Participants were more willing to offer attributions in an open-ended question. Only 8% attributed the cause of their pain to the heart directly. However, many named risk factors for heart disease. Almost two fifths (39%) blamed their lifestyle, nominating factors such as smoking, alcohol, bad diet, and lack of exercise. Nearly once third (31%) attributed it to stress and almost one quarter (23%) cited non-cardiac medical causes such as respiratory and gastrointestinal factors. Further research examining attributions through open-ended questions is necessary to understand how patients with NCCP make sense of their condition.

10.3.2.5 Service-related variables

Service-related questions have rarely been posed to patients with non-cardiac chest pain. When participants were asked whether they had been given an explanation of angina prior to testing, 9% claimed they had and a further 6% were unsure. This perceived diagnosis of angina prior to testing was reported by a low proportion of participants, but is nevertheless of concern. It is likely to greatly influence the way in which chest pain is interpreted and acted upon. At one-year follow-up, almost one third of participants (30%) perceived that they had not received their test results, the majority of whom (78%) were outpatients. While these participants may

indeed have been informed about their results, their perception that they have not is significant. It indicates that any information they may have been given was insufficient. In addition, the majority (66%) felt they had received no explanation for their chest pain. One other study has previously examined perceived explanations in patients with non-cardiac chest pain, with a higher proportion (81%) reporting they had received no explanation (Dumville et al., 2007).

10.3.3 Outcomes

10.3.3.1 Chest pain

At one-year follow-up, almost one third (31%) reported no further chest pain. Although the frequency and intensity of symptoms reduced significantly after one year, 69% continued to experience chest pain, nearly half of whom (46%) reported it at a frequency of at least once per month. The rate of persistent chest pain falls within the range of 40-90% reported in other studies. Eslick and Talley (2008b) reported the highest rate (90%) of persistent pain at two-year follow-up. However, the attrition rate was high, as just 65.5% of participants participated in the follow-up, and the follow-up sample may have been biased towards participants with ongoing symptoms. This study reported levels of persistent pain similar to Spalding and colleagues (2003), who found that symptoms were persistent in 61% of participants.

10.3.3.2 Health service use

Overall, 40% of participants with persistent chest pain reported persistent healthcare seeking behaviour during the one-year follow-up period. Almost one in ten of all participants returned to the emergency department for the investigation of chest pain. Although few studies have prospectively examined health service use in this patient group, a similar rate (14%) of emergency department utilisation within a one-year follow-up was found by Prina and colleagues (2004). However, the sample of 230 patients was recruited solely from the emergency room, and the profile of these patients is therefore likely to differ from the current sample. In this study, just over one half attended a cardiology clinic and nearly half attended

primary care in the year after initial recruitment. A higher level of primary care utilisation was found than by other studies. For example, Dumville and colleagues (2007) reported that 28% attended their primary care physicians within eight months following attendance at a rapid access chest pain clinic in England.

Although many participants (46%) were referred for further investigations, the majority were for cardiac tests. Despite the high prevalence of gastro-oesophageal disorders in patients with NCCP, only 8% were referred for gastrointestinal testing. Higher levels of referral to gastroenterology have been reported elsewhere (Eslick & Talley, 2008a). In a study in the United States of 205 primary care physicians, 30% of NCCP patients were referred to a gastroenterologist (Wong et al., 2005a). A rate of 15% has also been reported (Leise et al., 2010).

It is likely that the visitation to alternative therapists and psychologists was under-reported in this sample. In the qualitative study it was revealed that two of the participants had sought help from alternative therapists and psychologists, although they did not report this in the survey. The reluctance to report these visits may potentially indicate a perceived stigma attached to seeking help from these sources. There also appears to be a reluctance to accept a psychological cause, however, as indicated by the low participation rates in psychological interventions (Kisely et al., 2010). In addition, in a large study (n=807) of NCCP in primary care in Germany, only 6 patients visited a psychologist or psychiatrist in the 6-month follow-up, despite the coverage of psychological consultations by the healthcare system (Glombiewski et al., 2010).

10.3.4 Predictors of outcomes

In this study, the sample at follow-up was dichotomised into participants with improved versus persistent chest pain, and logistic regression analyses were conducted in order to examine the variables which predicted persistent pain. In addition, in order to examine predictors of persistent health service use for chest pain, the sample was divided into the three categories of: 1) no chest pain; 2) chest pain only; and 3) chest pain and health service use. Multinomial logistic regression

analyses were performed to examine which variables distinguished between these three groups. Previous literature findings will now be summarised before discussing the results of these analyses.

10.3.4.1 Literature findings

Very few studies have prospectively examined the outcomes of patients with NCCP. There is a dearth of research on the predictors of persistent chest pain, despite many cross-sectional studies examining co-morbid physical and psychosocial variables in NCCP. The most commonly examined physical factors have been gastro-oesophageal and musculoskeletal causes. Yet no studies have been identified as prospectively examining their relationship to persistent pain, and only one study has been identified as examining their relationship to persistent health service use. Eslick and Talley (2004b) found that acid regurgitation was associated with retrospective health service use, but this association was not found for heartburn and dysphagia. Psychological factors have been investigated more and have been shown to be associated with persistent pain, particularly panic disorder. The relationship between NCCP and persistent health service use is less well established, however, and many limitations in the literature have been highlighted. The relationship between cardiac anxiety and the outcomes of persistent pain and service use has not previously been examined in a prospective study. However, a recent RCT of cognitive-behavioural therapy for NCCP patients demonstrated that reduction in cardiac anxiety could account for improvement in pain (Spinhoven et al., 2011). The importance of cognitions in relation to persistent NCCP and service use has not been previously examined. Social and service-related factors have also been relatively neglected in the literature. Nevertheless, qualitative studies have indicated their relevance for poor outcomes.

10.3.4.2 Demographic variables

Employment status was the only demographic variable to significantly predict persistent NCCP, even when controlling for a range of physical, psychological and social factors. Those who were employed were less likely to report persistent symptoms. When participants with persistent symptoms were split into continued

service users and non-service users, employed participants were also less likely to be persistent service users. In the final multivariate model, employment remained a significantly unique predictor of persistent chest pain and associated health service use. Although no studies on non-cardiac chest pain have found associations between demographic variables and outcomes (Eslick & Talley, 2008a), the importance of demographic variables in studies of medically unexplained symptoms has been demonstrated. For example, in a study by Verhaak and colleagues (2006) in a general practice setting, older age, female gender, lower education, and lower socioeconomic status, as measured by public insurance and unemployment, were predictive of continued health service use.

10.3.4.3 Physical variables

When the physical variables were examined, heartburn at a frequency of at least once per month at baseline was associated with an increased risk of persistent NCCP. In a multivariate model predicting persistent NCCP that encompassed demographic, physical, psychological, and service-related variables, heartburn made a unique contribution to the model. When participants with continued symptoms were dichotomised into persistent and non-persistent service users, heartburn was only associated with participants reporting persistent symptoms and persistent service use. These findings are in contrast to Eslick and Talley (2004b), who found that acid reflux was significantly associated with retrospective healthcare seeking behaviour (OR=2.54, 95% CI 1.24-5.22, p=0.01), and not symptoms of heartburn. Healthcare use for the purpose of chest pain was not distinguished from other purposes, however. In addition, scheduled and unscheduled consulting were not examined separately.

Pain suggestive of a musculoskeletal origin at baseline also differentiated participants with persistent pain and service use. Furthermore, it was also associated with continued symptoms without further service use. The importance of gastro-oesophageal and musculoskeletal-like symptoms in predicting outcomes for NCCP patients has not previously been established. The results indicate that identifying NCCP patients with these co-morbid symptom characteristics could help

to identify patients for whom gastro-oesophageal and orthopaedic evaluations appear warranted (Husser, Bollmann, Kühne, Molling, & Klein, 2006).

10.3.4.4 Emotional variables

Although high levels of psychological distress were found, scores on the psychological variables of anxiety, depression, somatisation, and panic did not distinguish between those with improved and persistent pain. Other studies have shown associations between psychological variables and future symptoms, however. For example, Dammen and colleagues (2006) reported that participants with panic disorder were significantly more likely to have persistent chest pain at one-year follow-up. However, a higher rate of panic disorder was indicated by Dammen et al.'s sample (73% compared with 24%), which may account for the finding. Yet similar rates of panic disorder have been found in other studies. A study by Fleet and colleagues (2003) detected panic disorder in 27% of NCCP participants, as determined by diagnostic interviews. The discrepancy could be due to the recruitment of participants in these studies solely from the emergency department, or it may be due to measurement limitations.

Although psychological variables did not distinguish between participants with improved and persistent pain, they did distinguish between those with and without persistent service use for the investigation of further chest pain. Higher anxiety and depression scores were associated with greater statistically significant odds of reporting persistent healthcare-seeking behaviour. The findings are consistent with a study of 113 NCCP patients that demonstrated an association between anxiety disorders and increased healthcare use in the preceding year (White et al., 2008), yet this study did not show a similar association for mood disorders. The cross-sectional study did not control for chest pain commencement, however. The findings here are consistent with the general literature on health service use. Research has demonstrated that for a number of symptoms and illnesses, patients who continually seek care tend to have higher levels of psychological distress or anxiety (Petrie & Pennebaker, 2004). In contrast to findings from the general literature on medically unexplained symptoms, however, neither panic symptoms

nor somatisation were predictive of persistent chest pain and related service use in this study. As suggested earlier for the measurement of panic, the measurement of somatisation may also be problematic. In addition, there may not have been enough power to detect differences, since non-significant trends were detected (see section 8.3.4).

Cognitive-behavioural explanations for the role of anxiety and depression in healthcare-seeking behaviour have been offered. High levels of psychological distress are likely to be associated with greater introspection and stronger attention to bodily sensations (Petrie & Pennebaker, 2004; Petrie & Weinman, 2003). In addition, symptoms of psychological distress, such as tachycardia, can be misinterpreted as signs of physical illness (Petrie & Pennebaker, 2004).

The findings of this study do not appear to support the theory that psychological factors are implicated in the aetiology of all patients with NCCP. Psychological variables predicted persistent service use for chest pain, but did not distinguish those with persistent symptoms without further service use from those with no further symptoms. The recruitment of NCCP patients in most studies from hospital settings, particularly emergency departments, may be resulting in an over-estimation of levels of psychological distress and a subsequent false implication of psychological factors in the aetiology of NCCP. This study found lower levels of prospectively measured health service use, which may be due to recruitment from both inpatient and outpatient settings, as opposed to sole recruitment from one setting. A patient referred from primary care for cardiological assessment is likely to differ from a patient attending the emergency room. In this study, inpatients reported a more recent commencement of chest pain compared to outpatients. Inpatients were also less likely to have persistent chest pain and persistent health service use. Differences in the patient groups need to be accounted for.

The findings also highlight the danger of a reliance on cross-sectional findings. Although high levels of psychological morbidity have been demonstrated in this patient group, the relationship between psychological variables and persistent pain

and service use needs to be carefully examined before a psychological aetiology can be assumed.

10.3.4.5 Cardiac anxiety

Heart-focused or cardiac anxiety is arguably a type of health anxiety, which has been found to predict more severe illness and medical resource use in a variety of illnesses (Zvolensky, Eifert, Feldner, & Leen-Feldner, 2003). Baseline scores on the measure of cardiac anxiety – the CAQ – were significantly higher for patients with persistent NCCP. The overall scale significantly predicted continued symptoms, in addition to the subscales 'fear' and 'heart-focused attention'. When participants with continued chest pain were divided into those with continued healthcare use and those without, cardiac anxiety was only significantly associated with those with persistent service use. All three subscales of fear, avoidance, and attention were also associated with greater odds of service use. The scales did not distinguish those with continued symptoms without further service use from those without continued symptoms, thereby suggesting that cardiac anxiety is not implicated in the aetiology of NCCP, but rather the illness behaviour of those with NCCP. In a multivariate model encompassing demographic, physical, emotional, cognitive, social, and service-related variables, cardiac anxiety remained a unique predictor of persistent chest pain and related service use, compared to participants with no further pain.

A cross-sectional study previously demonstrated the significant relationship between cardiac anxiety and the reporting of chest pain symptoms (Zvolensky et al., 2003), but no prospective observational study examining its relationship to outcomes had previously been conducted. These findings are therefore a valuable contribution to the literature. A recent cognitive-behavioural therapy trial also found that reduced levels of cardiac anxiety measured by the CAQ mediated the reduction in NCCP post intervention (Spinhoven et al., 2011). Cardiac anxiety therefore appears to be a valuable construct in understanding NCCP and in developing interventions.

10.3.4.6 Cognitive variables

This is the first study to examine the relationship between illness perceptions and prospective outcomes of symptoms and service use in participants with NCCP. Illness perceptions as measured by the B-IPQ were important in distinguishing participants with persistent NCCP. Participants who perceived greater consequences, a chronic timeline, greater identity, more concern, and greater emotional affect had higher odds of persistent symptoms. At multivariate level, the perception of timeline remained statistically significant in distinguishing between the groups when all other perceptions were controlled for in the analysis. When participants with continued symptoms with and without persistent service use were examined separately, illness perceptions were not related to NCCP without service use, but were significantly related to NCCP with persistent healthcare utilisation. One other study examined illness perceptions in NCCP and their relationship to the outcome of reassurance one week and one month after exercise stress testing (Donkin et al., 2006). The same perceptions of consequences, timeline, identity, concern, and emotional affect were significantly predictive of reassurance and the perception of timeline was also significantly related to reassurance in multivariate models. The importance of illness perceptions in predicting outcomes supports the biopsychosocial model developed by Bass and Mayou (Bass & Mayou, 2002), which emphasises the importance of the interpretation of symptoms in determining outcomes.

Attributions did not significantly influence outcomes, yet the difficulties participants experienced in answering attribution questions discussed earlier (see section 10.2.2.5) may have accounted for this. The only exception was that a higher psychological attribution was related to persistent service use. Yet this significance disappeared once employment status and patient type were controlled for.

10.3.4.7 Social & service-related variables

When social and service-related variables were examined, perception of receipt of results was a statistically significant predictor of persistent NCCP. Those who

perceived that they received results were less likely to report NCCP at follow-up, while controlling for patient type and employment status and in the final multivariate model. This finding appears to be independent of patient type. Nevertheless, it was predominantly outpatients who reported not having received their test results. Although test result reports were sent to patients' primary care practitioners when a cardiology clinic appointment was not arranged, participants may have been given a general report that everything was fine without specific information on their EST, or they may not have followed up their results with their GP. A perceived receipt of test results almost reached significance in its association with persistent chest pain and health service use also. The results indicate the importance of clear communication with patients regarding the meaning of test results, as emphasised by a number of commentators (Mayou et al., 1999; Mukerji et al., 1993; Salmon et al., 1999). This is the first study to empirically demonstrate the relevance of this.

In order to examine exposure to heart disease, parental history of heart disease was examined, and participants with at least one parent with a medical history of heart disease were more likely to report chest pain without associated healthcare use at follow-up. The relationship remained significant while controlling for patient type and employment status. Only one other study has been identified as examining exposure to heart disease in NCCP (Aikens et al., 1999), which showed a cross-sectional relationship between exposure to siblings and friends with heart disease and intensity of chest pain. This study also demonstrated greater retrospective usage of the emergency department for chest pain, but this association was not observed in this prospective study. While there is tentative support for the hypothesis that more exposure to heart disease may be associated with persistent pain, further research is needed.

10.4 Summary of qualitative findings

The interpretative phenomenological analysis (IPA) of semi-structured interviews with participants with persistent NCCP aimed to explore the experiences of patients

in the context of receiving normal cardiac test results. It aimed to examine in greater detail how bodily sensations were interpreted and attributed. In particular, illumination on the influence of interactions with health services, which is difficult to ascertain quantitatively, was sought. After an idiographic, inductive, and iterative process of analysis, the following themes were identified: 1) disempowerment of normal test results; 2) limbo – inner struggle of negating and relating to potential causes; and 3) inadequacy of healthcare to validate and care for symptoms.

10.4.1 Disempowerment of normal test results

Participants felt disempowered by their lack of an abnormal test result. All participants conveyed a perceived sense of unworthiness of medical care and a feeling that their symptoms did not justify attending healthcare services. This sense of unworthiness was internalised to the effect that participants did not wish to speak about their symptoms due to their perceived insignificance. Most expressed a sense of hopelessness and a negative emotional impact associated with the lack of explanation for their chest pain. Participants sought to empower themselves by seeking information on the cause of their symptoms. However, the distressing nature of waiting for test results was emphasised. In addition, participants felt a lack of power to ask medical staff for information or elucidation, despite a will to discuss potential explanations. Other qualitative studies on patients with medically unexplained symptoms have demonstrated this sense of disempowerment. For example, in a study by Nettleton (2006) on neurology patients with unexplained symptoms, words such as "fraud," "fake," and "time waster" were commonly used throughout the interviews. In a qualitative study on chronic back pain (Rhodes, McPhillips-Tangum, Markham, & Klenk, 1999), participants reported feelings of shame and guilt and a sense of 'de-legitimation'.

Nettleton (2006) argued that people do not feel they have permission to be ill in the absence of a detectable physiological or pathological abnormality. Although the focus of medicine is on the detection of disease, the growth of the biopsychosocial model in medicine has widened the doctor's responsibility to psychosocial issues. However, Salmon and Hall (2003) argue that the dualism of mind and body is

retained within this model; "personality, emotion, behaviour or social circumstances are said to cause disease. The implication of this is that responsibility for disease is located in the mental, rational part of the individual. That is, because the rational patient has contributed to the disease, the patient incurs the responsibility that goes with culpability" (Salmon & Hall, 2003, p. 1973). Medically unexplained symptoms tend to be attributed to psychosocial factors, and patients are seen as partly responsible for their symptoms (Hatcher & Arroll, 2008).

It is argued that clinicians therefore do not feel responsible for the management of these patients, whom they perceive they cannot help (Salmon & Hall, 2003). In a qualitative study of 249 consultations between general practitioners and patients with medically unexplained symptoms (Salmon et al., 2007), all doctors 'criticised' their patients to various degrees. For example, one doctor claimed: "I think you're reading more into those symptoms than you ought to" (Salmon et al., 2007, p.456). Criticism was most commonly elicited when patients sought emotional support and not when they sought physical interventions. The authors concluded that doctors' criticism is motivated by a desire to reduce their patients' dependence on them.

10.4.2 Limbo - Inner struggle of negating and relating to potential causes

All participants struggled with coming to terms with their symptoms. Various potential causes were continually questioned and the very reality of the symptoms was also questioned. Every participant at one stage questioned whether their symptoms were imagined. The waiting for test results intensified the process of uncontrollable rumination and uncertainty. Participants attempted to relate to explanations offered by medical professionals or those deduced from their own reasoning. Some were able to re-attribute their symptoms from the heart to an alternative cause in light of this knowledge. More distress was observed when participants could not relate to any explanations, or the perceived attribution was not corroborated by medical staff.

Participants differed in their levels of acceptance of psychological attributions. For those who did not accept a psychological explanation, defensiveness and

annoyance was expressed, and a number of techniques were performed to negate a psychological attribution. For those who showed insight into the relationship between stress and worry and symptom experience, strategies for coping were more evident. Nevertheless, all participants demonstrated techniques to accept their symptoms including downplaying of symptoms, self-soothing inner dialogue, distraction, breathing, oppression of thoughts, and normalisation of pain.

Ambivalence and inner struggles about cause has been found in qualitative studies of other medically unexplained illnesses (e.g. Glenton, 2003). The participants similarly endured 'diagnostic limbo' and 'embodied doubt', as termed by Nettleton (2006; Nettleton et al., 2005). Petrie and Weinman (2006) have theorised that patients feel pressure to find a label or explanation for their symptoms, yet rudimentary knowledge of the body limits their ability to build models. If patients lack a satisfactory cognitive model, they are unable to interpret their symptoms as benign and further healthcare is sought (Petrie & Pennebaker, 2004). The findings of this study lend support to this theory, since participants lacking acceptable attributions demonstrated more distress. They also corroborate the findings of a qualitative study exploring the narratives that patients with unexplained symptoms constructed about their illness (Kirmayer, Groleau, Looper, & Dao, 2004). More distress was observed in participants who were unable to make sense of their symptoms.

10.4.3 Inadequacy of healthcare to validate and care for symptoms

The final theme that emerged from the data was the questioning of the adequacy of medical services to validate and care for NCCP. The futility of further healthcare-seeking behaviour was considered by the participants. The outstanding need for validation of symptoms was expressed by all but one interviewee (Mark). Interestingly, this interviewee had returned to the emergency department eight times in the preceding year. A perception of symptoms being invalidated may therefore act as a deterrent to seeking further medical care. For the other participants, a conflict was found between the desire for normal test results and the need for validation of symptoms. The perception of dismissiveness of medical

staff was experienced by the participants to varying degrees. The language in which participants predominantly described their hospital experiences conveyed a perceived sense of coldness and detachment on the part of medical staff. The same interviewee differed again in that he did not report feeling dismissed. It is possible that perceived dismissiveness and lack of validation for symptoms may act as deterrents to health service use.

Participants who had an acceptable model for understanding their chest pain, e.g. acceptance of a psychological cause, did not perceive a need for any additional healthcare. Three participants referred to the futility in further medical care due to the sense that potential tests had been exhausted. A sense of hopelessness was evident. One interviewee again differed from the other participants. Health service use offered him a legitimate way to excuse himself from work, but it was also a coping strategy for the alleviation of his severe symptoms. He did not appear to have developed alternative coping strategies other than use of medication and healthcare utilisation. The adequacy of the care the participants received was questioned by all but this interviewee. The receipt of insufficient information, unacceptable waiting times, a lack of answers, and even a lack of will on the part of clinicians to help were reported.

The participants in this study mirrored the findings of other studies on participants with unexplained symptoms in relation to perceptions of feeling rejected, being belittled, and being met with scepticism (Werner & Malterud, 2003). The need for validation has also been explored in patients with chronic unexplained back pain. A similar conflict between not wanting negative results and not wanting a serious disease to be detected has been found in this patient group (Glenton, 2003). The differing perspective of one of the participants (Mark) can be understood by examining the typology of frequent health service users developed by Dwamena and colleagues (2009). They classify patients with less psychological insight as feeling a strong entitlement to be excused from social obligations, and as seeking healthcare for symptom relief, legitimisation, and support. The participant appears to characterise this patient type, lending support to the classification.

In the biomedical approach, doctors have responsibility for and authority over disease prediction, detection, and treatment in the body (Salmon & Hall, 2003). Yet, when faced with unexplainable symptoms, doctors report feeling 'heart-sink' due to their inability to help (O'Dowd, 1988). The participants appear to have interpreted an inability to help as a lack of validation for their symptoms. They therefore see further healthcare use as futile.

10.4.4 Relationship of qualitative findings to cohort study findings

While over two thirds of participants reported continued chest pain, only 40% of these participants sought ongoing medical help. The disempowerment experienced by participants may help explain why a high proportion of participants with persistent symptoms did not seek further medical care. This service-related factor is not accessible by survey methods; interpretation of participants' illness narratives was needed to access this experience of patients with NCCP. The dynamic nature of cognitions and behaviours when confronted with a health threat are rarely captured by questionnaire-based methods (Senior et al., 2002). The perceptions of illness emerged as important factors in the experience of chest pain in both the quantitative and qualitative findings. However, the chaotic nature of participants' sense-making of their symptoms was not captured in the observational study, although it clearly emerged as a predominant theme in the qualitative analysis.

The IPA study also helps illuminate how participants decide on their attributions. A dynamic process of relating to and negating potential explanations and attributions was interpreted. The exploration of multifaceted attributions was also facilitated by qualitative inquiry. The need for qualitative studies of symptoms appraisal and attributions to complement quantitative measures has been advocated by many (Deary, Chalder, & Sharpe, 2007; French & Weinman, 2007; Petrie & Weinman, 2003). Questioning of the adequacy of medical care to fulfil the needs of the participants also helps the understanding of persistent service use. The perception that symptoms were unworthy of medical care and the sense of being dismissed from services seemed to deter participants from seeking further care. The cohort

study was unable to assess these factors, although attempts to operationalise service-related variables were made. The qualitative findings enhanced understanding of the quantitative findings.

10.5 Implications for interventions and practice

Participants with NCCP are clearly not a homogenous group of patients. Physical, psychological, social, and service-related factors are likely to interact in various ways across different individuals. Despite the heterogeneity, results of the prospective cohort study indicated a number of predictors of outcomes. Based on these results, the targeting of heartburn, musculoskeletal pain, anxiety, depression, cardiac anxiety, communication about results, and negative illness perceptions has the potential to improve outcomes. Heartburn and cardiac anxiety were uniquely significant predictors of outcomes in multivariate analyses. The findings therefore indicate that interventions targeting the assessment and treatment of a potential gastro-oesophageal or musculoskeletal cause and the amelioration of cardiac anxiety are likely to be of benefit. Low levels of referral to gastroenterology were reported in this study, in comparison to the international literature. Due to the predictive value of these physical symptoms in determining worse outcomes for patients, greater referral rates should be considered.

According to the qualitative analysis, the experience of disempowerment and the lack of validation for symptoms may actually be facilitating lower levels of persistent service use. Yet patients should not be forced to suffer in silence. The constant questioning of cause was very evident and having an explanation they could relate to appeared to improve coping and reduce the distress associated with a lack of explanation. In the cohort study, participants who did not perceive to receive their test results were more likely to report persistent chest pain. Providing patients with an explanation they perceive as acceptable and adequate in explaining their chest pain is therefore indicated. However, if patients feel that their symptoms have not been dismissed and invalidated, they may be more willing to accept the undetermined nature of the cause.

Despite significant advances in technology and knowledge, uncertainty remains a ubiquitous aspect of medical care (Arrow, 1963; Fox, 1980; Luther & Crandall, 2011). Yet both the medical community and patients generally show little tolerance for uncertainty and ambiguity which can lead to mutual frustration (Luther & Crandall, 2011). Patients with medically unexplained symptoms are often referred to with pejorative language such as "thick folder patients" or "frequent fliers" (Hatcher & Arroll, 2008). Among physicians, intolerance to uncertainty has been shown to be associated with an increased tendency towards excessive diagnostic test referrals and a failure to follow evidence-based guidelines (Ghosh, 2004; Luther & Crandall, 2011). Enhancing doctors' skills in managing uncertainty and managing patients' expectations may improve outcomes. Although general practitioners are used to managing uncertainty, most hospital settings operate with differential diagnoses and once potentially serious causes have been eliminated, little further care or information is provided.

Due to the heterogeneity of the patient group, an individualised, multi-dimensional approach to healthcare appears warranted. Interventions conducted with this patient group have primarily consisted of cognitive-behavioural therapy (CBT). Although modest effect sizes have been demonstrated for the interventions (Kisely et al., 2010), the acceptability of psychological interventions is questionable. Only five out of the ten trials included in a systematic review reported on participation rates, the rate of which ranged from 40% to 60% (Kisely et al., 2010). A further 20% were lost to follow-up and a larger attrition rate of 35% was reported by two of the trials. Trials examining the benefit of antidepressants have also been conducted (e.g. Mayou & Sharpe, 1997; Smith et al., 2006). Although high levels of psychological morbidity are found in this patient group, psychological distress was not found to predict persistent chest pain in this study, and very few studies have examined its prospective relationship to outcomes. The use of medication for this patient group is therefore premature, and the findings highlight the danger of relying on cross-sectional findings. Further observational studies are needed that examine predictors of persistent symptoms and service use in order to aid the

design of optimal interventions that are acceptable to patients. The potential benefit of targeting cardiac anxiety has been highlighted by this study.

A number of guidelines for doctors dealing with medically unexplained symptoms have been proposed. Hatcher and Arroll (2008) advise that all symptoms should be treated seriously, regardless of cause, and that doctors should provide patients with a model for managing the condition. Dwamena and colleagues (2009) also recommend the provision of a model for understanding their illness, following an elicitation of the patient's views and concerns. Due to the anxiety-provoking nature of being sent for cardiac testing, as illuminated in the qualitative analysis, the meaning of a normal test result should be explained prior to testing in addition to other possible causes of symptoms (Hatcher & Arroll, 2008). The provision of information on possible causes prior to exercise stress testing has been shown to improve reassurance levels one month after testing (Donkin et al., 2006). The findings also have implications for medical education. As Luther and Crandall (2011) argue, the teaching of the fundamentally ambiguous and uncertain nature of medicine should be integrated into every medical school curriculum. It is claimed that even textbooks of clinical diagnosis are written as though uncertainty does not exist (Glasziou, Burls, & Gilbert, 2008).

Aside from patient and clinician interventions, structural changes are also necessary for the improvement of the adequacy of care for this patient group. Waiting periods for the receipt of test results are unacceptable. Patients may have to wait up to six months to get the result of their exercise stress test, during which time they are left to ruminate over the potential outcome of the result. Kisely and Simon (2006) also highlight the need for longer consultations and the potential benefit of collaborative care arrangements with mental health specialists, if necessary. Rapid access chest pain clinics (RACPC) or chest pain units – service models which are beginning to be adopted in Ireland - may provide a better alternative to the current predominant system.

Although evidence is yet to be established for RACPCs (Wood, Timmis, & Halinen, 2001), the speedy assessment and diagnosis process is likely to limit negative perceptions and higher levels of cardiac anxiety from becoming entrenched in the minds of patients. They have been argued to have value in both reducing medical costs and patient distress (Capewell & McMurray, 2000). The development of primary healthcare centres in Ireland also holds promise for the development of collaborative care approaches (Department of Health & Children, 2001). A collaborate, stepped-care approach has been advocated both specifically for patients with NCCP (Bass & Mayou, 2002), and more generally for patients with medically unexplained physical symptoms (Huang & McCarron, 2011).

10.6 Personal reflection

On a personal level, I feel I have gained a considerable insight into the experience of NCCP, and in the process, I have learned how to deal with the challenges encountered in conducting research in a clinical setting. My previous lack of understanding of chest pain and health service pathways for the investigation of chest pain necessitated a reliance on other medical professionals. My lack of clinical knowledge also meant I was heavily reliant on staff for guidance and support. Patients did not always recognise my lack of expertise, however, and often looked to me for guidance on their symptoms. Although I desperately wanted to support them, not only did I not have the clinical expertise, but any information I had provided them with could have influenced follow-up assessments. This restriction was a personal struggle for me.

Another struggle of mine was the quick realisation that our current health system lacks the structures and supports to care for the psychosocial needs of patients. This is not unique to NCCP patients, but can be extrapolated to many other unexplained symptoms and conditions. The dismissiveness of psychosocial causes was palpable. One of the participants who screened positive for depression telephoned me in a heightened state of arousal due to his unhappiness over the way his symptoms had been dismissed as depression by his general practitioner. I

began to dread a participant screening positive for depression, as I feared that other patients would be met with the same dismissiveness. While some staff were supportive and caring, the lack of understanding of psychosocial causes of pain became quickly apparent. Some participants were also highly defensive about the use of psychological measures. This was perhaps due to previous experience of having felt that their symptoms were not believed.

There are some very caring and highly skilled medical practitioners working with patients, but they are not equipped and/or do not have the resources to manage these patients effectively. Unfortunately, the needs of these patients are unlikely to be met in the near future, unless a change in the structuring of healthcare occurs. The translation of this research into improved understanding and management is critical in order to improve outcomes.

10.7 Recommendations and future directions

NCCP is clearly a complex symptom associated with multiple factors across a wide range of domains. Few studies have previously examined predictors of change in symptoms and healthcare utilisation, and further observational studies are needed in order to build upon the evidence provided here. This is necessary due to the heterogeneity of the patient group and the likelihood of different findings in different healthcare settings.

Strong evidence was provided in the study for the role of high levels of cardiac anxiety in predicting persistent chest pain and service use. Attempts to lower levels of cardiac anxiety are therefore likely to result in improved outcomes for these patients. Preliminary evidence for this has been provided by the recent CBT trial in which reductions in cardiac anxiety mediated the subsequent reduction in non-cardiac chest pain compared to placebo (Spinhoven et al., 2011). Although it is unlikely that interventions will eliminate NCCP completely, the identification of patients with modifiable predictors of symptoms and service use will likely result in improved outcomes for these patients.

Evidence for the optimal treatment setting for patients is also needed. The usefulness of a stepped care or a collaborative care approach needs to be determined so as to inform the management of patients. The impact of improvements in doctor-patient communication and the provision of acceptable explanations on patient outcomes should also be examined. The subsequent likelihood of increased empowerment of patients may improve their outcomes. Despite an absence of labelled disease, patients should not feel unworthy of care or advice. Society has become reliant on the medical testing process to detect and determine the cause of symptoms. When it is unable to do so, blame should not be shifted to the patients, but rather efforts should be made to effectively reassure patients and reduce their health anxiety.

10.7.1 Key recommendations for practice

- A speedy assessment and diagnosis process should be performed with NCCP patients.
- Other possible explanations for chest pain should be provided prior to testing, in addition to explaining the meaning of a normal cardiac test result.
- Patients should be aided in developing an acceptable causal model to understand their pain and the symptom should not be dismissed.
- Due to the heterogeneity of NCCP patients, an individualised, multi-dimensional approach to its management should be adopted.
- Patients with persistent pain for whom a possible gastro-oesophageal or musculoskeletal cause is indicated should be referred for appropriate testing and/or treatment.
- Interventions targeting cardiac anxiety and illness perceptions are likely to result in improved outcomes in terms of persistent pain and health service use.
- Targeting psychological factors in patients with psychological morbidity is likely to reduce healthcare utilisation.
- Enhancing doctors' skills in managing uncertainty and managing patients' expectations may improve outcomes.

10.7.2 Key recommendations for research

- Longitudinal studies on this patient group are needed to examine the prospective relationship of variables in relation to the outcomes of patients.
- Due to the multi-dimensional factors associated with NCCP, factors should not be examined in isolation, and a cross-disciplinary approach is necessary. Interactions between physical, psychosocial, and service-related factors also need to be explored.
- The sample of NCCP patients needs to be clearly defined, with transparent inclusion and exclusion criteria and unambiguous definitions.
- In order to limit selection bias, patients should be recruited from a wide variety of settings including the emergency room, chest pain clinics, outpatient departments, and primary care settings.
- The targeting of illness perceptions and cardiac anxiety in interventions is likely to be associated with positive outcomes.
- Methods to distinguish discrete types of NCCP patients need to be developed so that interventions can be tailored appropriately.
- Interventions that are acceptable to patients need to be developed.
- The best setting for the management of NCCP needs to be determined. The general practitioner is likely to be valuable in bridging between specialties.
- Further exploration of the doctor's perspective in managing NCCP is needed so that barriers and facilitators to improved management can be determined.

10.8 Conclusions

This study reported on the symptom experiences of 145 participants with chest pain who attended exercise stress testing and had normal test results. These participants were labelled as having non-cardiac chest pain (NCCP). At one-year follow-up, almost one third reported no further chest pain, with 69% reporting continued pain. In addition, nearly half of participants had returned to their general practitioner and one in ten attended the emergency department in the intervening

year for the investigation of chest pain. The predictive value of physical, psychological, social, and service-related variables were examined in relation to the two outcome variables of persistent NCCP and persistent health service use. Very few studies have previously examined predictors of these outcomes; the majority of studies on the topic are cross-sectional in design.

Regarding demographic variables, employed participants had lower odds of reporting persistent chest pain and persistent health service use, even when controlling for a range of physical and psychosocial factors. Heartburn at a frequency of at least once per month at baseline was also associated with both persistent NCCP and persistent health service at one year. Higher scores on the psychological variables of anxiety and depression did not distinguish participants with persistent NCCP from those with no further pain, but did distinguish participants with persistent health service use for chest pain. Greater cardiac anxiety was also predictive of persistent pain and related service use. The illness perceptions of consequences, timeline, identity, illness concern, and emotional affect were associated with both outcome variables also. Additionally, participants recruited as inpatients were more likely to report persistent pain and service use, and those who perceived that they had not received their test results were more likely to report persistent NCCP.

Analysis of the semi-structured in-depth interviews with six of the participants revealed three predominant themes: 1) the disempowerment of normal test results; 2) limbo - inner struggle of negating and relating to potential causes; and 3) the inadequacy of healthcare to validate and care for symptoms. Participants differed in their relationship to these three themes, yet this variability illuminated the dynamic process of interpreting symptoms, and the impact of clinical consultations on the perceived futility of healthcare-seeking behaviour.

Patients with NCCP are clearly not a homogenous patient group. Nevertheless, a number of predictors of outcomes were identified which can inform the development of interventions. In particular, the results indicate that interventions

targeting the assessment of a potential gastro-oesophageal or musculoskeletal cause and the reduction of cardiac anxiety are likely to improve outcomes in these patients. Improved communication about the meaning of test results is also indicated. The qualitative analysis highlighted the importance of having an acceptable cognitive model with which to interpret chest pain symptoms. Increased communication with doctors about potential causes may decrease patient distress and healthcare utilisation. Due to the heterogeneity of patients, individualised, stepped-care appears warranted.

Although a clear understanding of the aetiology and maintenance of non-cardiac chest pain remains elusive, Buetow (2011) argues that uncertainty in medicine should be viewed as a virtue since it promotes a critical attitude, reflection, and deliberation, all of which will be needed in future work on this topic.

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Appendices

Appendix A: Letter of Invitation

Website: www.beaumont.ie

Ospidéal Beaumont

BEAUMONT HOSPITAL
P. O. Box 1297 Beaumont Road Dublin 9
Telephone: 809 3000 / 837 7755 Facsimile: 837 6982

Department of Cardiology

Date

Dear _____

We are writing to you to inform you about a research study being carried out at Beaumont Hospital in association with the Royal College of Surgeons in Ireland. This study is being done to examine the experiences and outcomes of patients referred for exercise stress testing.

Patients who do not have a confirmed diagnosis of heart disease and are being referred for exercise stress testing at Beaumont Hospital are being invited to take part. Participation is entirely voluntary and will not have any effect on your medical care. We will not be informed of who decides to participate.

Enclosed is some information about the study. Please read this in your own time. A researcher will contact you after 10 days to check you are suitable to take part and to tell you more about the study before you decide to participate or not. If you do not wish to be contacted further about the study, please call or email the ECG secretary in the mean time to say so. Her details are as follows:

Name: Melanie Campbell
Telephone: (01) 8092444
Email: melaniecampbell@beaumont.ie

Yours sincerely,

Professor David Foley
Consultant Cardiologist
Tel: (01) 8093140

Dr Brendan McAdam
Consultant Cardiologist
Tel: (01) 8093366

Dr Thomas Gumbrielle
Consultant Cardiologist
Tel: (01) 8093067

Dr Richard Sheahan
Consultant Cardiologist
Tel: (01) 8093061

Appendix B: Information Leaflet (inpatients)

Website: www.beaumont.ie

Ospidéal Beaumont

BEAUMONT HOSPITAL
P. O. Box 1297 Beaumont Road Dublin 9
Telephone: 809 3000 / 837 7755 Facsimile: 837 6982

Inpatient Information Leaflet

Study Title:

Health and service use in patients referred for exercise stress testing

Principal investigator's Name: **Aisling Sheehan**
Telephone No. of Principal Investigator: **01 4028586 / 087 9476366**

1. Introduction

You are being invited to take part in a research study carried out at Beaumont Hospital in association with the Health Services Research Centre of the Royal College of Surgeons in Ireland. The study is being done to investigate the experiences and outcomes of patients referred for exercise stress testing. Before you decide whether or not you wish to take part, you should read the information provided below carefully.

Participation is voluntary and you will receive the same treatment whether or not you decide to participate. You may quit at any time without having to give a reason for your decision and without any negative impact on the care you receive now or in the future.

2. Why is this study being done?

This study aims to examine the experiences and health outcomes of patients referred for an exercise stress test. It will explore patient symptoms and health, as well as health service use. We hope the study will give us information that will improve the care of patients in the future.

3. How will it be carried out?

Patients who do not have a confirmed diagnosis of heart disease and are being referred for exercise stress testing at Beaumont Hospital are invited to take part. About 200 people will take part in the study and about 20 participants will be interviewed in detail about their experiences.

4. Who is organising and funding this study?
The Principal Investigator is funded by the Health Research Board to conduct this study. The research will go towards a PhD qualification.

5. What will happen to me if I agree to take part?
- You will fill out a consent form and a questionnaire and the researcher will ask you a few short questions about your health care. This should take about 30 minutes in total.
- One week after your test, the researcher will send you a short questionnaire asking about how you feel about your test and about your views. This will take about 5-10 minutes to complete.
- You will be contacted 12 months later to see what has happened and/or changed since your exercise stress test. This will involve a short telephone call and a questionnaire similar to the one completed before your test.
- You will be given the option of agreeing to take part in an interview. After 12 months, about 20 participants will be asked to talk about their experiences in more detail with the researcher. This will take place in a setting of your choice at a time that suits you and will last about an hour.

6. What are the benefits?
You will not benefit directly from participation. It is hoped that the findings will benefit future patients by informing the development of services.

7. What are the risks?
There are no risks to taking part in the study. However, if you think that any of the questions are very distressing, you do not have to answer them and we would urge you to talk to your doctor.

8. Will there be any additional costs involved?
You will be given pre-paid envelopes to return completed questionnaires. If you are invited for an interview and have travel costs,

you will be reimbursed. However, you will be given the opportunity to have the interview in your home.

9. Will I get the results back?

You will be provided with an informative one-page summary of findings by post when the study is finished, but you will not be sent individual results. In addition, you will be offered the opportunity to discuss the results with the researcher.

10. Confidentiality

- All information will remain strictly confidential at all times. Your name will not be published and your answers will not be given to anyone outside the researchers. However, if any participants' answers indicate that they are very distressed, we will inform them and their medical team so that any relevant follow-up can be made and patient welfare can be protected.
- Your details and results will be coded and only the research team will be able to find out your identity. Anonymous data will be stored for 7 years after publication of results and then destroyed, in accordance with guidelines.
- The researcher is not a hospital employee. With the permission of your doctor, she will be looking at your medical charts to gather information on medication, hospital visits, and diagnostic tests. Your patient records will remain the property of the hospital and will not be removed from the hospital.

11. Permission

The study has hospital Research Ethics Committee approval.

12. Further information

If you have any further questions about the study, or if you would like more information now or any future time, please contact:

Name: Ms Aisling Sheehan, BA
Address: Division of Population Health Sciences, Royal College of Surgeons in Ireland, 123 St. Stephen's Green, Dublin 2
Phone No: 01 4028586 / 087 9476366

Appendix C: Information Leaflet (outpatients)

Website: www.beaumont.ie

Ospidéal Beaumont

BEAUMONT HOSPITAL
P. O. Box 1297 Beaumont Road Dublin 9
Telephone: 809 3000 / 837 7755 Facsimile: 837 6982

Outpatient Information Leaflet

Study Title:

Health and service use in patients referred for exercise stress testing

Principal Investigator's Name: **Aisling Sheehan**
Telephone No. of Principal Investigator: **01 4028586 / 087 9476366**

1. Introduction
You are being invited to take part in a research study carried out at Beaumont Hospital in association with the Health Services Research Centre of the Royal College of Surgeons in Ireland. The study is being done to investigate the experiences and outcomes of patients referred for exercise stress testing. Before you decide whether or not you wish to take part, you should read the information provided below carefully.

Participation is voluntary and you will receive the same treatment whether or not you decide to participate. You may quit at any time without having to give a reason for your decision and without any negative impact on the care you receive now or in the future.

2. Why is this study being done?
This study aims to examine the experiences and health outcomes of patients referred for an exercise stress test. It will explore patient symptoms and health, as well as health service use. We hope the study will give us information that will improve the care of patients in the future.

3. How will it be carried out?
Patients who do not have a confirmed diagnosis of heart disease and are being referred for exercise stress testing at Beaumont Hospital are

invited to take part. About 200 people will take part in the study and about 20 participants will be interviewed in detail about their experiences.

4. Who is organising and funding this study?

The Principal Investigator is funded by the Health Research Board to conduct this study. The research will go towards a PhD qualification.

5. What will happen to me if I agree to take part?

- Before your test, you will fill out a consent form and a questionnaire. This should take about 25 minutes to complete. You will return these to the researcher when you meet her at your exercise stress test appointment. She will then ask you a few short questions about your health care.
- One week after your test, the researcher will send you a short questionnaire asking about how you feel about your test and about your views. This will take about 5-10 minutes to complete.
- You will be contacted 12 months later to see what has happened and/or changed since your exercise stress test. This will involve a short telephone call and a questionnaire similar to the one completed before your test.
- You will be given the option of agreeing to take part in an interview. After 12 months, about 20 participants will be asked to talk about their experiences in more detail with the researcher. This will take place in a setting of your choice at a time that suits you and will last about an hour.

6. What are the benefits?

You will not benefit directly from participation. It is hoped that the findings will benefit future patients by informing the development of services.

7. What are the risks?

There are no risks to taking part in the study. However, if you think that any of the questions are very distressing, you do not have to answer them and we would urge you to talk to your doctor.

8. Will there be any additional costs involved?

You will be given pre-paid envelopes to return completed questionnaires. If you are invited for an interview and have travel costs,

you will be reimbursed. However, you will be given the opportunity to have the interview in your home.

9. Will I get the results back?
You will be provided with an informative one-page summary of general findings by post when the study is finished. In addition, you will be offered the opportunity to discuss the results with the researcher.

10. Confidentiality
- All information will remain strictly confidential at all times. Your name will not be published and your answers will not be given to anyone outside the researchers. However, if any participants' answers indicate that they are very distressed, we will inform them and their GP so that any relevant follow-up can be made and patient welfare can be protected.
- Your details and results will be coded and only the research team will be able to find out your identity. Anonymous data will be stored for 7 years after publication of results and then destroyed, in accordance with guidelines.
- The researcher is not a hospital employee. With the permission of your doctor, she will be looking at your medical charts to gather information on medication, hospital visits, and diagnostic tests. Your patient records will remain the property of the hospital and will not be removed from the hospital.

11. Permission
The study has hospital Research Ethics Committee approval.

12. Further information
If you have any further questions about the study, or if you would like more information now or any future time, please contact:

Name: Ms Aisling Sheehan, BA
Address: Division of Population Health Sciences, Royal College of Surgeons in Ireland, 123 St. Stephen's Green, Dublin 2
Phone No: 01 4028586 / 087 9476366

Appendix D: Consent Form

CONSENT FORM

Study Title:

Health and service use in patients referred for exercise stress testing

Participant No:

Please tick the appropriate answer.

I confirm that I have read and understood the Patient Information Leaflet and have had the opportunity to ask questions and discuss the study. I have received satisfactory answers to all of my questions.	□ **Yes**	□ **No**
I understand that my participation is completely **voluntary** and that I may withdraw at any time, without giving reason, and without this decision affecting my medical care.	□ **Yes**	□ **No**
I understand that my identity will remain strictly confidential. However, if my answers indicate that I am very distressed, this will be discussed with me and my medical team / GP will be informed.	□ **Yes**	□ **No**
I understand that sections of my medical records may be viewed by the researcher.	□ **Yes**	□ **No**
I have been given a copy of the Patient Information Leaflet and this Consent form for my records.	□ **Yes**	□ **No**
I agree to take part in this study	□ **Yes**	□ **No**

Signature _____ Date _____

Name in block capitals _____

To be completed by the Principal Investigator or his nominee.

I the undersigned, have taken the time to fully explained to the above patient the nature and purpose of this study in a manner that he/she could understand. I have explained all steps to the study and have invited him/her to ask questions on any aspect of the study that concerned them.

_____	_____	_____	_____
Signature:	Name in Block Capitals:	Qualification:	Date:

Appendix E: Questionnaire (T1)

Health and service use in patients referred for exercise stress testing

Thank you for participating in this survey

Participant No: _____

Date of exercise stress test: _____

Home Telephone No: _____

Mobile Telephone No: _____

Today's date: _____

Section A

WE BEGIN WITH SOME QUESTIONS ABOUT YOUR CHEST DISCOMFORT. YOUR SYMPTOMS ARE PERSONAL TO YOU AND MAY INCLUDE PALPITATIONS, BREATHLESSNESS OR PAIN.

(Please put a tick (✓) in the appropriate box)

A1 How long have you been on the waiting list for your exercise stress test? (Please indicate in hours/days/months)
I have been waiting _____

A2 Chest discomfort is any sensations you feel inside your chest. How **many times** have you had chest discomfort **in the past 12 months?**

1 ☐ None
2 ☐ Once
3 ☐ Less than once a month
4 ☐ About once a month
5 ☐ About once a week
6 ☐ Several times a week
7 ☐ Daily

A3 At its **worst**, how **bad** has your chest discomfort been **in the past 12 months?**

1 ☐ **Mild** - can be ignored if I don't think about it
2 ☐ **Moderate** - cannot be ignored, but it does not affect my lifestyle
3 ☐ **Severe** - affects my lifestyle
4 ☐ **Very severe** - markedly affects my life-style

A4 When the chest discomfort occurs, **how long** does it **usually** last?

1 ☐ Less than one minute
2 ☐ 1 minute to less than 5 minutes
3 ☐ 5 minutes to 15 minutes
4 ☐ 15 minutes to 30 minutes
5 ☐ 30 minutes to 60 minutes
6 ☐ More than 1 hour

A5 When in your life did this chest discomfort **first** begin, as close as you can recall?

1 ☐ In the last 3 months
2 ☐ In the last 6 months
3 ☐ More than 6 months to 1 year ago
4 ☐ More than 1 year to 2 years ago
5 ☐ More than 2 years to 5 years ago
6 ☐ More than 5 years to 10 years ago
7 ☐ More than 10 years to 20 years ago
8 ☐ More than 20 years ago

For the next 3 questions, please place a **vertical mark** on the line to indicate how bad you feel your pain is in relation to the two extremes.
For example, if you were feeling mild pain, you might mark the line as follows:

No pain ——|—————————— Very severe pain

For example, if you were feeling severe pain, you might mark the line as follows:

No pain ——————————|— Very severe pain

A6 How severe is your pain at its worst? Place a **vertical mark** on the line below to indicate how bad you feel your pain is at its **worst**.

No Pain ——————————————— Very severe

A7 How severe is your pain at its least? Place a **vertical mark** on the line below to indicate how bad you feel your pain is at its **least**.

No Pain ——————————————— Very severe

A8 How severe is your pain on average? Place a **vertical mark** on the line below to indicate how bad you feel your pain is **on average**.

No Pain ——————————————— Very severe

A9 Do you get this discomfort when you walk uphill or hurry?

1 ☐ Yes 2 ☐ No 3 ☐ Unable

A10 Do you get this discomfort when you walk at an ordinary pace on level ground?

1 ☐ Yes 2 ☐ No 3 ☐ Unable

A11 What do you do if you get it while you are out walking?

1 ☐ Stop or slow down
2 ☐ Carry on

A12 If you stand still, what happens to it?

1 ☐ Relieved 2 ☐ Not relieved

A13 How soon?

1 ☐ 10 minutes or less 2 ☐ More than 10 minutes

A14 Does the chest discomfort get worse when you take a deep breath and/or cough?

1 ☐ No
2 ☐ Yes

A15 Do any of the following movements make the discomfort worse? (tick all that apply)

1 ☐ No effect on moving
2 ☐ Moving arms
3 ☐ Rolling over in bed
4 ☐ Bending over
5 ☐ Bending sideways
6 ☐ Walking
7 ☐ Running

A16 **Interference:**

Please **circle** the one number that describes how your discomfort has interfered with various aspects of your life:

1. General Activity										
0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes
2. Mood										
0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes
3. Walking Ability										
0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes
4. Normal Work (includes both work outside the home and housework)										
0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes
5. Relations with other people										
0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes
6. Sleep										
0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes
7. Enjoyment of life										
0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes

A17 Cardiac Concerns:

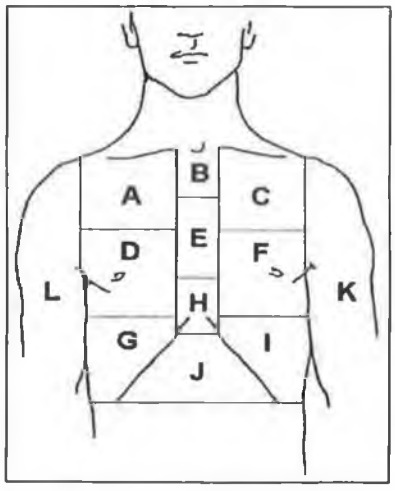
Please **circle** the one number that best applies to you.

		Never	Rarely	Some-times	Often	Always
1	I pay attention to my heart beat	0	1	2	3	4
2	I avoid physical exertion	0	1	2	3	4
3	My racing heart wakes me up at night	0	1	2	3	4
4	Chest pain/discomfort wakes me up at night	0	1	2	3	4
5	I take it easy as much as possible	0	1	2	3	4
6	I check my pulse	0	1	2	3	4
7	I avoid exercise or other physical work	0	1	2	3	4
8	I can feel my heart in my chest	0	1	2	3	4
9	I avoid activities that make my heart beat faster	0	1	2	3	4
10	If tests come out normal, I still worry about my heart	0	1	2	3	4
11	I feel safe being around a hospital, physician or other medical facility	0	1	2	3	4
12	I avoid activities that make me sweat	0	1	2	3	4
13	I worry that doctors do not believe my symptoms are real	0	1	2	3	4

When I have chest discomfort or when my heart is beating fast:

14	I worry that I may have a heart attack	0	1	2	3	4
15	I have difficulty concentrating on anything else	0	1	2	3	4
16	I get frightened	0	1	2	3	4
17	I like to be checked out by a doctor	0	1	2	3	4
18	I tell my family or friends	0	1	2	3	4

A18 Please look at the diagram (below). What is the **main location** of the **chest discomfort** you are currently experiencing? (You may select more than one; circle the letter(s) where you have chest pain).



Section B
NEXT, WE ASK YOU SOME QUESTIONS ABOUT YOUR HEALTH
(Please put a tick (✓) in the appropriate box)

B1 During the **past 4 weeks**, how much have you been bothered by any of the following problems?

	Symptom	Not bothered at all	Bothered a little	Bothered a lot
a	Stomach pain	☐	☐	☐
b	Back pain	☐	☐	☐
c	Pain in your arms, legs, or joints (knees, hips, etc.)	☐	☐	☐
d	Menstrual cramps or other problems with your periods [Women only]	☐	☐	☐
e	Headaches	☐	☐	☐
f	Chest pain	☐	☐	☐
g	Dizziness	☐	☐	☐
h	Fainting spells	☐	☐	☐
i	Feeling your heart pound or race	☐	☐	☐
j	Shortness of breath	☐	☐	☐
k	Pain or problems during sexual intercourse	☐	☐	☐
l	Constipation, loose bowels, or diarrhoea	☐	☐	☐
m	Nausea, gas, or indigestion	☐	☐	☐
n	Feeling tired or having low energy	☐	☐	☐
o	Trouble sleeping	☐	☐	☐

	Yes	No
In the past 4 weeks, have you had an anxiety attack - suddenly feeling fear or panic?	☐	☐

Section C

NEXT WE ASK SOME QUESTIONS ABOUT HEARTBURN.

IN THIS SURVEY, "HEARTBURN" MEANS A BURNING PAIN OR DISCOMFORT BEHIND THE BREAST BONE IN YOUR CHEST. WHEN ANSWERING THESE QUESTIONS, PLEASE DO NOT COUNT ANY OTHER SENSATIONS AS "HEARTBURN"

(Please put a tick (✓) in the appropriate box)

C1 Have you **ever** had a **burning feeling** rising from your stomach or lower chest up towards your neck?

1 ☐ No → **skip to D1**
2 ☐ Yes

C2 How many times have you had heartburn **in the past 12 months?**

1 ☐ None
2 ☐ Less than once a month
3 ☐ About once a month
4 ☐ About once a week
5 ☐ Several times a week
6 ☐ Daily

C3 **In the past 12 months**, how bad was your heartburn usually?

1 ☐ Mild – can be ignored if I don't think about it
2 ☐ Moderate – cannot be ignored, but it does not affect my life-style
3 ☐ Severe – affects my life-style
4 ☐ Very severe – markedly affects my life-style

Section D

NEXT WE ASK SOME QUESTIONS ABOUT ACID REGURGITATION.

"ACID REGURGITATION" IS A BITTER OR SOUR TASTING FLUID COMING UP INTO YOUR THROAT OR MOUTH.

(Please put a tick (✓) in the appropriate box)

D1 Have you **ever** had acid regurgitation?

1 ☐ No → **skip to E1**
2 ☐ Yes

D2 How many times have you had acid regurgitation **in the past 12 months**?

1 ☐ None
2 ☐ Less than once a month
3 ☐ About once a month
4 ☐ About once a week
5 ☐ Several times a week
6 ☐ Daily

D3 How bad has your acid regurgitation been **in the past 12 months?**

1 ☐ Mild – can be ignored if I don't think about it
2 ☐ Moderate – cannot be ignored, but it does not affect my life-style
3 ☐ Severe – affects my life-style
4 ☐ Very severe – markedly affects my life-style

Section E

NEXT WE ASK SOME QUESTIONS ABOUT TROUBLE SWALLOWING IN THE PAST 12 MONTHS.

"TROUBLE SWALLOWING" IS A FEELING THAT FOOD STICKS IN YOUR THROAT OR CHEST

(Please put a tick (✓) in the appropriate box)

E1 Have you **ever** had difficulty swallowing?

1 ☐ No → **skip to F1**
2 ☐ Yes

E2 How many times have you had trouble swallowing **in the past 12 months?**

1 ☐ None
2 ☐ Less than once a month
3 ☐ About once a month
4 ☐ About once a week
5 ☐ Several times a week
6 ☐ Daily

E3 How bad has your trouble swallowing usually been **in the past 12 months?**

1 ☐ Mild – can be ignored if I don't think about it
2 ☐ Moderate – cannot be ignored, but it does not affect my life-style
3 ☐ Severe – affects my life-style
4 ☐ Very severe – markedly affects my life-style

Section F

NEXT WE ASK SOME QUESTIONS ABOUT YOUR PSYCHOLOGICAL WELL-BEING. PLEASE INDICATE WHICH REPLY COMES CLOSEST TO HOW YOU HAVE BEEN FEELING IN THE PAST WEEK.

(Please put a tick (✓) in the appropriate box)

1. I feel tense or 'wound up': 3☐ Most of the time 2☐ A lot of the time 1☐ From time to time, occasionally 0☐ Not at all	**8. I feel as if I am slowed down:** 3☐ Nearly all the time 2☐ Very often 1☐ Sometimes 0☐ Not at all
2. I still enjoy the things I used to enjoy: 0☐ Definitely as much 1☐ Not quite so much 2☐ Only a little 3☐ Hardly at all	**9. I get a sort of frightened feeling like 'butterflies' in the stomach:** 0☐ Not at all 1☐ Occasionally 2☐ Quite often 3☐ Very often
3. I get a sort of frightened feeling as if something awful is about to happen: 3☐ Very definitely and quite badly 2☐ Yes, but not too badly 1☐ A little, but it doesn't worry me 0☐ Not at all	**10. I have lost interest in my appearance:** 3☐ Definitely 2☐ I don't take as much care as I should 1☐ I may not take quite as much care 0☐ I take just as much care as ever
4. I can laugh and see the funny side of things: 0☐ As much as I always could 1☐ Not quite so much now 2☐ Definitely not so much now 3☐ Not at all	**11. I feel restless as if I have to be on the move:** 3☐ Very much indeed 2☐ Quite a lot 1☐ Not very much 0☐ Not at all
5. Worrying thoughts go through my mind: 3☐ A great deal of the time 2☐ A lot of the time 1☐ From time to time but not too often 0☐ Only occasionally	**12. I look forward with enjoyment to things:** 0☐ As much as ever 1☐ Rather less than I used to 2☐ Definitely less than I used to 3☐ Hardly at all
6. I feel cheerful: 3☐ Not at all 2☐ Not often 1☐ Sometimes 0☐ Most of the time	**13. I get sudden feelings of panic:** 3☐ Very often indeed 2☐ Quite often 1☐ Not very often 0☐ Not at all
6. I can sit at ease and feel relaxed: 0☐ Definitely 1☐ Usually 2☐ Not often 3☐ Not at all	**14. I can enjoy a good book or radio or TV programme:** 0☐ Often 1☐ Sometimes 2☐ Not often 3☐ Very seldom

Section G
NEXT WE ASK ABOUT YOUR VIEWS ABOUT YOUR SYMPTOMS

Listed below are a number of symptoms that you may or may not have experienced. Please indicate by **circling Yes or No**, whether you have experienced any of these symptoms since your chest discomfort. If 'Yes', then please say whether you believe that these symptoms are related to your chest discomfort.

	I have experienced this symptom since my chest discomfort			**This symptom is related to my chest discomfort**	
1. Chest pain	No	Yes	→	No	Yes
2. Neck/jaw discomfort	No	Yes	→	No	Yes
3. Nausea	No	Yes	→	No	Yes
4. Breathlessness	No	Yes	→	No	Yes
5. Pain in arm	No	Yes	→	No	Yes
6. Pain in back	No	Yes	→	No	Yes
7. Feeling tired	No	Yes	→	No	Yes
8. Gastric discomfort (e.g. heartburn)	No	Yes	→	No	Yes
9. Wheeziness	No	Yes	→	No	Yes
10. Upset Stomach	No	Yes	→	No	Yes
11. Sleep Difficulties	No	Yes	→	No	Yes
12. Dizziness	No	Yes	→	No	Yes
13. Light-headedness	No	Yes	→	No	Yes
14. Loss of Strength	No	Yes	→	No	Yes

For the following questions, please **circle** the number that best corresponds to **your views**:

1. How much do your symptoms affect your life?

0 1 2 3 4 5 6 7 8 9 10

no affect at all — severely affects my life

2. How long do you think your symptoms will continue?

0 1 2 3 4 5 6 7 8 9 10

a very short time — forever

3. How much control do you feel you have over your symptoms?

0 1 2 3 4 5 6 7 8 9 10

absolutely no control — extreme amount of control

4. How much do you think your treatment can help your symptoms?

0 1 2 3 4 5 6 7 8 9 10

not at all — extremely helpful

5. How much do you experience symptoms?

0	1	2	3	4	5	6	7	8	9	10
no symptoms at all										many severe symptoms

6. How concerned are you about your symptoms?

0	1	2	3	4	5	6	7	8	9	10
not at all concerned										extremely concerned

7. How well do you feel you understand your symptoms?

0	1	2	3	4	5	6	7	8	9	10
Don't understand at all										understand very clearly

8. How much do your symptoms affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

0	1	2	3	4	5	6	7	8	9	10
Not at all affected emotionally										extremely affected emotionally

CAUSES OF MY ILLNESS

We are interested in what you consider may have been the cause of your chest discomfort. We are most interested in your own views about the factors that caused your chest discomfort, rather than what others, including doctors or other family members, may have suggested to you.

Please list the factors that you now believe caused **YOUR** chest discomfort.

The most important causes for me:

1. _____
2. _____
3. _____

To what degree do you consider that the following possible causes may have contributed to **YOUR** chest discomfort? (Circle the appropriate number)

	not at all related to my pain						related to very high degree
Heart/cardiac disease	1	2	3	4	5	6	7
Stomach/digestive disorder	1	2	3	4	5	6	7
Lung/breathing disorder	1	2	3	4	5	6	7
Psychological factors	1	2	3	4	5	6	7

Section H

NEXT, WE ASK YOU SOME QUESTIONS ABOUT YOUR HEALTH CARE AND EXPOSURE TO HEART PROBLEMS.

(Please put a tick (✓) in the appropriate box)

H1 Has your doctor ever told you that your chest discomfort is due to angina?

1 ☐ No
2 ☐ Yes
3 ☐ I do not know

H2 Have you been given any other explanations? (Please give details below)

_____

_____

_____

H3 How satisfied are you with the explanations you have been given about your chest discomfort?

1 ☐ Not satisfied at all
2 ☐ Mostly dissatisfied
3 ☐ Somewhat satisfied
4 ☐ Mostly satisfied
5 ☐ Highly satisfied

H4 To what extent do you feel that you have been given consistent information and/or advice about your chest discomfort?

1 ☐ Not at all consistent
2 ☐ Mostly inconsistent
3 ☐ Somewhat consistent
4 ☐ Mostly consistent
5 ☐ Always consistent

H5 How many of your parents, other family members, and close friends had or have a heart condition? (Please given the number in the space provided)

	Number with heart conditions
Parents	_____
Other family members	_____
Close Friends	_____

H6 Are you currently taking any cardiac medication?

1 ☐ Yes
2 ☐ No

Section I
WE FINISH BY ASKING SOME GENERAL QUESTIONS ABOUT YOURSELF
(Please put a tick (✓) in the appropriate box for each question)

I1 Are you (tick answer):

1 ☐ Male
2 ☐ Female

I2 Your date of birth is: ☐☐ / ☐☐ / ☐☐☐☐
Day Month Year

I3 What is your **current** marital status? (tick one only)

1 ☐ Single (never married)
2 ☐ Cohabiting
3 ☐ Married
4 ☐ Separated
5 ☐ Divorced
6 ☐ Widowed

I4 Which best describes the **highest** level of education you have completed to date?

1 ☐ Some primary school (not complete)
2 ☐ Primary or equivalent
3 ☐ Intermediate/ Junior/ Group Certificate or equivalent
4 ☐ Leaving Certificate or equivalent
5 ☐ Diploma/ Certificate
6 ☐ Primary degree (university)
7 ☐ Postgraduate/ Higher degree (university)

I5 Which of these descriptions **best** describes your **usual situation** in regard to work? (tick one only)

1 ☐ Employee (incl. apprenticeship or Community Employment)
2 ☐ Self-employed outside farming
3 ☐ Farmer
4 ☐ Student full-time
5 ☐ On State/Government training scheme (FÁS, Fáilte Ireland etc.)
6 ☐ Unemployed, actively looking for a job
7 ☐ Long-term sickness or disability
8 ☐ Home duties / looking after the home or family
9 ☐ Retired
10 ☐ Other (specify) _____

I6 What is your occupation/ occupation of principal earner in your household? (or most recent former occupation if retired)
[If relevant, record the rank or grade e.g. rank in army, grade in civil service. If farmer, record number of acres farmed]

_____

I7 If self employed or farmer, how many employees (if any) do/did you have?

_____ employees

I8 If working as employee, self-employed or farmer, how many hours do/did you normally work per week, including any regular overtime work? If you work at more than one job, please include the hours in all jobs.

_____ hours

I9 If working as employee, do you supervise or manage any personnel in your job?

☐ Yes → How many? _____
☐ No

I10 If retired or unemployed, in what year did you last work? _____

I11 Are you covered by a medical card?

1 ☐ Yes – full medical card
2 ☐ Yes – GP only medical card
3 ☐ No

I12 Are you (also) covered by private health insurance (through VHI, BUPA, Quinn, or any other health insurance company) either in your own name or through another family member?

1 ☐ Yes, in own name
2 ☐ Yes, through family member
3 ☐ Not medically insured

I13 Please provide the name and address of your GP

GP Name: _____

GP Address: _____

_____

THANK YOU FOR YOUR HELP AND PARTICIPATION IN THIS SURVEY

We plan to have another phase of this research project where we hope to talk to some patients to find out how you are doing in more detail. This involves an interview in a setting of your choice. If you are willing to be invited for interview, please tick below. Please remember that you can of course decide not to take part in any future research at any time.

- ☐ Yes, it is ok to contact me again about an interview
- ☐ No, I do not wish to be re-contacted

Appendix F: T1 Health Service Use Questionnaire

HEALTH SERVICE USE (T1)

Participant No: _____
Date: _____

1 Have you visited any health care professionals about your **chest discomfort <u>in the past 12 months</u>?** How many times? (tick each one that applies).

Health Care Professional	Attendance in the past 12 months	No. of visits in the past 12 months about chest pain					
		0	1	2	3 to 5	6 to 9	10 or more
Family doctor / GP	☐ Yes ☐ No	☐	☐	☐	☐	☐	☐
Accident & Emergency (Casualty Department)	☐ Yes ☐ No	☐	☐	☐	☐	☐	☐
Cardiologist (i.e. heart specialist)	☐ Yes ☐ No	☐	☐	☐	☐	☐	☐
Gastroenterologist (i.e. stomach and digestive specialist)	☐ Yes ☐ No	☐	☐	☐	☐	☐	☐
Respiratory specialist (i.e. lung / breathing specialist)	☐ Yes ☐ No	☐	☐	☐	☐	☐	☐
Alternative therapist (homeopath, naturopath, acupuncturist or similar)	☐ Yes ☐ No	☐	☐	☐	☐	☐	☐
Counsellor / Psychologist / Psychiatrist	☐ Yes ☐ No	☐	☐	☐	☐	☐	☐
Other: _____	☐ Yes ☐ No	☐	☐	☐	☐	☐	☐

2 Have you been **admitted** to hospital <u>**in the last 12 months**</u>? If so, please indicate how many times and how many nights you were in hospital in total.

Hospital Admission	No. of hospital admissions	Total bed nights in hospital
☐ Yes ☐ No	_____ admissions	_____ nights

3 Are you currently on a **waiting list** for any of these health care professionals? If so, **how long** you have been on the waiting list? (tick each one that applies)

	YES		How long on the waiting list?
Cardiologist (i.e. heart specialist)	☐ Yes ☐ No	If ticked →	_____ weeks
Gastroenterologist (i.e. stomach and digestive specialist)	☐ Yes ☐ No	If ticked →	_____ weeks
Respiratory specialist (i.e. lung / breathing specialist)	☐ Yes ☐ No	If ticked →	_____ weeks

4 Have you visited different physicians/hospitals? (Probe details on how many and for what reasons)

_____

_____

_____

5 Have you ever had any of the following **procedures for investigation of chest discomfort?** (tick all that apply) If so, please indicate the number of times you have had each procedure.

	No.		No.
Electrocardiogram ☐		**CT Angiogram** ☐	
Chest x ray ☐		**Esophagoscopy** ☐	
Echocardiography ☐		**Intravascular ultrasound** ☐	
Stress echocardiography ☐		**Endoscopic ultrasound** ☐	
Coronary angiography ☐		**Reflux testing** ☐	
Chest radiograph ☐		**MRI** ☐	
Exercise electrocardiogram ☐		**Other** ☐ _____	

6 When is a good time to contact you?

_____

Appendix G: Letter of invitation (T2)

Website: www.beaumont.ie

Ospidéal Beaumont

BEAUMONT HOSPITAL
P. O. Box 1297 Beaumont Road Dublin 9
Telephone: 809 3000 / 837 7755 Facsimile: 837 6983

Date

Dear _____,

I am writing to you about the health study you are participating in on chest discomfort, which is being carried out at Beaumont Hospital in association with the Health Services Research Centre of the Royal College of Surgeons in Ireland. You kindly filled out a survey before your exercise stress test a year ago. We are now following everyone up to ask about their health and health care. We are interested in finding out what has happened and/or changed since your test and about your health care experience.

Please find the follow-up survey with this letter. We are asking you to fill this out and return it with the free-post envelope provided. I will also contact you by telephone within a few weeks to ask a further few questions which should take about 5 minutes. I will be happy to answer any questions you may have about the study at this time.

Participation is completely voluntary and you can withdraw from the study at any time. All information you give us is strictly confidential. However, if participants' answers indicate they may be depressed, we will inform them and their GP so that any relevant follow-up can be made and patient welfare can be protected.

We hope the results of this study will give us information that will improve the care of patients. We therefore greatly appreciate your participation.

I look forward to speaking with you.

Many thanks,

_____

Aisling Sheehan, BA

Contact Details

Address: Division of Population Health Sciences, RCSI, 123 St. Stephen's Green, Dublin 2
Telephone: (01) 402 8586 / 087 9476366
Email: aislingsheehan@rcsi.ie

Appendix H: Follow-Up Letter of Invitation (T2)

Website: www.beaumont.ie

Ospidéal Beaumont

BEAUMONT HOSPITAL
P. O. Box 1297 Beaumont Road Dublin 9
Telephone: 809 3000 / 837 7755 Facsimile: 837 6982

Date

Dear _____,

I am writing to you about the health study you are participating in on chest discomfort, which is being carried out at Beaumont Hospital in association with the Health Services Research Centre of the Royal College of Surgeons in Ireland. You kindly filled out a survey before your exercise stress test a number of months ago. We are now following everyone up to ask about their health and health care. We are interested in finding out what has happened and/or changed since your test and about your health care experience.

We sent you a follow-up survey recently and are re-sending a copy of the survey with this letter as a reminder. We would be grateful if you could fill this out and return it with the free-post envelope provided.

Participation is completely voluntary and you can withdraw from the study at any time. All information you give us is strictly confidential. However, if participants' answers indicate they may be depressed, we will inform them and their GP so that any relevant follow-up can be made and patient welfare can be protected.

We hope the results of this study will give us information that will improve the care of patients. We therefore greatly appreciate your participation.

Many thanks,

_____

Aisling Sheehan, BA

Contact Details
Address: Division of Population Health Sciences, RCSI, 123 St. Stephen's Green, Dublin 2
Telephone: (01) 402 8586 / 087 9476366
Email: aislingsheehan@rcsi.ie

Appendix I: Questionnaire (T2)

Health and service use in patients referred for exercise stress testing

Follow up

Thank you for participating in this survey.

Please try to answer every question.

Participant No: ☐☐☐

Today's Date: _____

Section A

We begin with some questions about your chest discomfort. Your symptoms are personal to you and may include palpitations, breathlessness or pain.

(Please put a tick (✓) in the appropriate box)

A1 Chest discomfort is any sensations you feel inside your chest. How **many times** have you had chest discomfort **in the past 12 months?**

1 ☐ None ---→ If none, please skip to **Question B1, Pg 4**
2 ☐ Once
3 ☐ Less than once a month
4 ☐ About once a month
5 ☐ About once a week
6 ☐ Several times a week
7 ☐ Daily

A2 At its **worst**, how **bad** has your chest discomfort been **in the past 12 months?**

1 ☐ **Mild** - can be ignored if I don't think about it
2 ☐ **Moderate** - cannot be ignored, but it does not affect my lifestyle
3 ☐ **Severe** - affects my lifestyle
4 ☐ **Very severe** - markedly affects my life-style

A3 **How long** does the chest discomfort **usually** last?

1 ☐ Less than one minute
2 ☐ 1 minute to less than 5 minutes
3 ☐ 5 minutes to 15 minutes
4 ☐ 15 minutes to 30 minutes
5 ☐ 30 minutes to 60 minutes
6 ☐ More than 1 hour

A4 For the following, please **circle** the number that best corresponds to **your views**:

1. How much do your symptoms affect your life?

0	1	2	3	4	5	6	7	8	9	10
no affect at all										severely affects my life

2. How long do you think your symptoms will continue?

0	1	2	3	4	5	6	7	8	9	10
a very short time										forever

3. How much control do you feel you have over your symptoms?

0	1	2	3	4	5	6	7	8	9	10
absolutely no control										extreme amount of control

4. How much do you think your treatment can help your symptoms?

0	1	2	3	4	5	6	7	8	9	10
not at all										extremely helpful

5. How much do you experience symptoms?

0	1	2	3	4	5	6	7	8	9	10
no symptoms at all										many severe symptoms

6. How concerned are you about your symptoms?

0	1	2	3	4	5	6	7	8	9	10
not at all concerned										extremely concerned

7. How well do you feel you understand your symptoms?

0	1	2	3	4	5	6	7	8	9	10
Don't understand at all										understand very clearly

8. How much do your symptoms affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)

0	1	2	3	4	5	6	7	8	9	10
Not at all affected emotionally										extremely affected emotionally

A5 Interference:

Please **circle** the one number that best describes how your discomfort has **interfered** with various aspects of your life:

1. General Activity										
0	1	2	3	4	5	6	7	8	9	10
Does not Interfere									Completely	Interferes
2. Mood										
0	1	2	3	4	5	6	7	8	9	10
Does not Interfere									Completely	Interferes
3. Walking Ability										
0	1	2	3	4	5	6	7	8	9	10
Does not Interfere									Completely	Interferes
4. Normal Work (includes both work outside the home and housework)										
0	1	2	3	4	5	6	7	8	9	10
Does not Interfere									Completely	Interferes

5. Relations with other people										
0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes
6. Sleep										
0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes
7. Enjoyment of life										
0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes

Section B

Next, we ask you some questions about your cardiac concerns.

(Please put a tick (✓) in the appropriate box)

B1 Cardiac concerns:

Please **circle** the one number that best applies to you.

		Never	Rarely	Some-times	Often	Always
1	I pay attention to my heart beat	0	1	2	3	4
2	I avoid physical exertion	0	1	2	3	4
3	My racing heart wakes me up at night	0	1	2	3	4
4	Chest pain/discomfort wakes me up at night	0	1	2	3	4
5	I take it easy as much as possible	0	1	2	3	4
6	I check my pulse	0	1	2	3	4
7	I avoid exercise or other physical work	0	1	2	3	4
8	I can feel my heart in my chest	0	1	2	3	4
9	I avoid activities that make my heart beat faster	0	1	2	3	4
10	If tests come out normal, I still worry about my heart	0	1	2	3	4
11	I feel safe being around a hospital, physician or other medical facility	0	1	2	3	4
12	I avoid activities that make me sweat	0	1	2	3	4
13	I worry that doctors do not believe my symptoms are real	0	1	2	3	4

When I have chest discomfort or when my heart is beating fast:

14	I worry that I may have a heart attack	0	1	2	3	4
15	I have difficulty concentrating on anything else	0	1	2	3	4
16	I get frightened	0	1	2	3	4
17	I like to be checked out by a doctor	0	1	2	3	4
18	I tell my family or friends	0	1	2	3	4

Section C

Next, we ask you some questions about your health.

(Please put a tick (✓) in the appropriate box)

C1 During the **past 4 weeks**, how much have you been bothered by any of the following?

	Symptom	Not bothered at all	Bothered a little	Bothered a lot
a	Stomach pain	☐	☐	☐
b	Back pain	☐	☐	☐
c	Pain in your arms, legs, or joints (knees, hips, etc.)	☐	☐	☐
d	Menstrual cramps or other problems with your periods [Women only]	☐	☐	☐
e	Headaches	☐	☐	☐
f	Chest pain	☐	☐	☐
g	Dizziness	☐	☐	☐
h	Fainting spells	☐	☐	☐
i	Feeling your heart pound or race	☐	☐	☐
j	Shortness of breath	☐	☐	☐
k	Pain or problems during sexual intercourse	☐	☐	☐
l	Constipation, loose bowels, or diarrhoea	☐	☐	☐
m	Nausea, gas, or indigestion	☐	☐	☐
n	Feeling tired or having low energy	☐	☐	☐
o	Trouble sleeping	☐	☐	☐

In the past 4 weeks, have you had an anxiety attack - suddenly feeling fear or panic?	**Yes** ☐	**No** ☐

Section G

Next we ask some questions about your psychological well-being. Please indicate which reply comes closest to how you have been feeling in the past week.

(Please put a tick (✓) in the appropriate box)

1. I feel tense or 'wound up': 3☐ Most of the time 2☐ A lot of the time 1☐ From time to time, occasionally 0☐ Not at all	**9. I feel as if I am slowed down:** 3☐ Nearly all the time 2☐ Very often 1☐ Sometimes 0☐ Not at all
2. I still enjoy the things I used to enjoy: 0☐ Definitely as much 1☐ Not quite so much 2☐ Only a little 3☐ Hardly at all	**9. I get a sort of frightened feeling like 'butterflies' in the stomach:** 0☐ Not at all 1☐ Occasionally 2☐ Quite often 3☐ Very often
3. I get a sort of frightened feeling as if something awful is about to happen: 3☐ Very definitely and quite badly 2☐ Yes, but not too badly 1☐ A little, but it doesn't worry me 0☐ Not at all	**10. I have lost interest in my appearance:** 3☐ Definitely 2☐ I don't take as much care as I should 1☐ I may not take quite as much care 0☐ I take just as much care as ever
4. I can laugh and see the funny side of things: 0☐ As much as I always could 1☐ Not quite so much now 2☐ Definitely not so much now 3☐ Not at all	**12. I feel restless as if I have to be on the move:** 3☐ Very much indeed 2☐ Quite a lot 1☐ Not very much 0☐ Not at all
5. Worrying thoughts go through my mind: 3☐ A great deal of the time 2☐ A lot of the time 1☐ From time to time but not too often 0☐ Only occasionally	**12. I look forward with enjoyment to things:** 0☐ As much as ever 1☐ Rather less than I used to 2☐ Definitely less than I used to 3☐ Hardly at all
6. I feel cheerful: 3☐ Not at all 2☐ Not often 1☐ Sometimes 0☐ Most of the time	**13. I get sudden feelings of panic:** 3☐ Very often indeed 2☐ Quite often 1☐ Not very often 0☐ Not at all
7. I can set at ease and feel relaxed: 0☐ Definitely 1☐ Usually 2☐ Not often 3☐ Not at all	**14. I can enjoy a good book or radio or TV programme:** 0☐ Often 1☐ Sometimes 2☐ Not often 3☐ Very seldom

Section H

Next we ask about your views about your symptoms.

H1 Cause of My Illness

We are interested in what **you think** may have been the **cause** and/or continues to be the cause of your chest discomfort. We are most interested in **your own views** about what **caused your chest discomfort**, rather than what others, including doctors or other family members, may have suggested to you.

Please list the most important factors for you:

1. _____
2. _____
3. _____

H2 On a scale of 1 to 7, how much do you think the following possible causes may have contributed to **your** chest discomfort? (Circle the appropriate number)

	not at all related to my pain						related to very high degree
Heart/cardiac disease	1	2	3	4	5	6	7
Stomach/digestive disorder	1	2	3	4	5	6	7
Lung/breathing disorder	1	2	3	4	5	6	7
Psychological factors	1	2	3	4	5	6	7

Section I

Next we ask some questions about your reassurance.

Please **circle** the one number that best describes how you feel about the following questions:

I1 How worried are you about your health?

1	2	3	4	5	6	7	8	9	10
Not at all									extremely worried

I2 **Do you believe there is something seriously wrong with your heart?**

1	2	3	4	5	6	7	8	9	10
not at all									strongly believe

I3 **Were you reassured by your exercise stress test?**

1	2	3	4	5	6	7	8	9	10
not at all									completely reassured

I4 **How accurate do you think the test was for identifying heart problems?**

1	2	3	4	5	6	7	8	9	10
not at all									extremely accurate

I5 **Do you believe you need further testing to find the cause of your chest discomfort?**

1	2	3	4	5	6	7	8	9	10
not at all									definitely

Section J

Finally, we ask you some questions about your health care for any chest discomfort since your exercise stress test (EST).

(Please put a tick (✓) in the appropriate box)

J1 Have you attended **Accident and Emergency** since your EST because of chest discomfort?

0 ☐ No ----------→ **Skip to J3**
1 ☐ Yes

J2 How **many times** have you attended **Accident and Emergency**?

1 ☐ Once
2 ☐ Twice
3 ☐ 3 times
4 ☐ 4 times
5 ☐ 5 times
6 ☐ 6 times or more

J3 Have you been to visit your **GP** about any chest discomfort since your EST?

0 ☐ No ----------→ **Skip to J5**
1 ☐ Yes

J4 How **many times** have you attended your **GP** where you discussed chest discomfort and/or tests for chest discomfort?

1 ☐ Once	4 ☐ 5-6 times	7 ☐ About once a week
2 ☐ Twice	5 ☐ 7-8 times	8 ☐ More than once a week
3 ☐ 3-4 times	6 ☐ About once a month	

J5 Have you seen a **cardiologist** / heart doctor since your EST?

0 ☐ No ----------→ **Skip to J7**
1 ☐ Yes

J6 How **many times** have you seen a **cardiologist**?

1 ☐ Once	4 ☐ 4 times
2 ☐ Twice	5 ☐ 5 times
3 ☐ 3 times	6 ☐ 6 times or more

J7 Have you seen any **other specialist** for the investigation of chest discomfort since your EST?

0 ☐ No ----------→ **Skip to J9**
1 ☐ Yes

J8 Which of the following **specialists** have you seen?

1 ☐ Gastroenterologist	4 ☐ Psychologist
2 ☐ Respiratory specialist	5 ☐ Other: _____
3 ☐ Alternative Therapist	

J9 Are you currently taking any **medication** for your **heart?**

0 ☐ No
1 ☐ Yes

J10 Were you given the **results** of your **exercise stress test?**

0 ☐ No ----------→ **Skip to J12**
1 ☐ Yes

J11 **How** did you get the results?

1 ☐ GP / Family Doctor
2 ☐ Doctor while patient in Beaumont Hospital
3 ☐ Clinic appointment at Beaumont Hospital
4 ☐ Other: _____

J12 **What explanation** (if any) were you given for your chest discomfort? (Please give details)

_____

_____

_____

_____

J13 How **satisfied** are you with the **explanations and information** you have been given by your health care providers?

1 ☐ Not satisfied at all
2 ☐ Mostly dissatisfied
3 ☐ Somewhat satisfied
4 ☐ Mostly satisfied
5 ☐ Highly satisfied

Finally, if you have any **comments** you would like to make, please do so in the space provided below.

_____

_____

_____

_____

_____

_____

_____

Many thanks for completing this survey.
Your participation is greatly appreciated.

Appendix J: Telephone Questionnaire (T2)

If returned questionnaire: ask questions in shadow ☐☐☐

Date: _____ Participant No.

Section A: Pain

At the time of your exercise stress test __ months ago, you had been experiencing some chest discomfort. Chest discomfort is any sensations you feel inside your chest. Your symptoms are personal to you_and may include palpitations, breathlessness or pain.

A1. Since your test, have you had any chest discomfort?

0 ☐ No ----------→ **Skip to B1**
1 ☐ Yes

A2. How **many times** have you had chest discomfort **in the past 12 months?**

2 ☐ Once
3 ☐ Less than once a month
4 ☐ About once a month
5 ☐ About once a week
6 ☐ Several times a week
7 ☐ Daily

A2. At its **worst**, how **bad** has it been **in the past 12 months?**

1 ☐ **Mild** – can be ignored if I don't think about it
2 ☐ **Moderate** – cannot be ignored, but it does not affect my lifestyle
3 ☐ **Severe** – affects my lifestyle
4 ☐ **Very severe** – markedly affects my life-style

A3. On a scale of 1 to 10, 1 being not at all and 10 being completely, how much does your chest discomfort interfere with your life?

1 2 3 4 5 6 7 8 9 10

Section B: Health Service Use

I would now like to ask a few questions about your health care since your test __ months ago. I am interested in any health care you have received not only at Beaumont Hospital but also any other doctor or hospital you may have visited.

B1 Have you attended **Accident and Emergency** since your EST because of chest discomfort?

0 ☐ No ----------→ **Skip to B6**
1 ☐ Yes

B2 How **many times** have you attended **Accident and Emergency**?

1 ☐ Once
2 ☐ Twice
3 ☐ 3 times
4 ☐ 4 times
5 ☐ 5 times
6 ☐ 6 times or more

B3 How many times at Beaumont Hospital? _____

B4 Were you admitted to hospital?

0 ☐ No ----------→ **Skip to B6**
1 ☐ Yes

B5 How many bed nights did you stay at hospital? _____

B6 Have you been to visit your **GP** about any chest discomfort since your EST?

0 ☐ No ----------→ **Skip to B8**
1 ☐ Yes

B7 How **many times** have you attended your **GP** where you discussed chest discomfort and/or tests for chest discomfort?

1 ☐ Once
2 ☐ Twice
3 ☐ 3-4 times
4 ☐ 5-6 times
5 ☐ 7-8 times
6 ☐ About once a month
7 ☐ About once a week
8 ☐ More than once a week

B8 Have you seen a **cardiologist** / heart doctor since your EST?

0 ☐ No ----------→ **Skip to B11**
1 ☐ Yes

B9 How **many times** have you seen a **cardiologist**?

1 ☐ Once
2 ☐ Twice
3 ☐ 3 times
4 ☐ 4 times
5 ☐ 5 times
6 ☐ 6 times or more

B10 How many times at Beaumont Hospital? _____

B11 Have you seen any **other specialist** for the investigation of chest discomfort since your EST?

0 ☐ No ----------→ **Skip to B13**
1 ☐ Yes

B12 Which of the following **specialists** have you seen?

1 ☐ Gastroenterologist
2 ☐ Respiratory specialist
3 ☐ Alternative Therapist
4 ☐ Psychologist
5 ☐ Other: _____

B13 Have you had another exercise stress test since your EST?

0 ☐ No
1 ☐ Yes

B14 Have you had an angiogram since your test?

0 ☐ No
1 ☐ Yes

B15 Did you have any other tests for the investigation of your chest discomfort?

0 ☐ No ----------→ **Skip to B17**
1 ☐ Yes

B16 What tests did you have?

_____

_____

B17 Are you currently waiting for any tests or clinic appointments?

0 ☐ No ----------→ **Skip to B19**
1 ☐ Yes

B18 What tests/clinics are you waiting for?

_____

_____

B19 Are you currently taking any **medication** for your **heart?**

0 ☐ No
1 ☐ Yes

B20 Were you given the **results** of your **exercise stress test?**

0 ☐ No ----------→ **Skip to J12**
1 ☐ Yes

B21 **How** did you get the results?

1 ☐ GP / Family Doctor
2 ☐ Doctor while patient in Beaumont Hospital
3 ☐ Clinic appointment at Beaumont Hospital
4 ☐ Other: _____

B22 **What explanation** (if any) were you given for your chest discomfort? (Please give details)

_____

_____

_____

Section C: Attributions & Reassurance

C1 Cause of My Illness

We are interested in what **you think** may have been the **cause** and/or continues to be the cause of your chest discomfort. We are most interested in **your own views** about what **caused your chest discomfort**, rather than what others, including doctors or other family members, may have suggested to you.

Please list the most important factors for you:

1. _____ 2. _____

3. _____

C2 Attributions

On a scale of 1 to 7, how much do you think the following possible causes may have contributed to **your** chest discomfort? (Circle the appropriate number)

	not at all related to my pain						**related to very high degree**
Heart/cardiac disease	1	2	3	4	5	6	7
Stomach/digestive disorder	1	2	3	4	5	6	7
Lung/breathing disorder	1	2	3	4	5	6	7
Psychological factors	1	2	3	4	5	6	7

C3 Reassurance

I1 **How worried are you about your health?**

1 2 3 4 5 6 7 8 9 10

Not at all extremely worried

I2 Do you believe there is something seriously wrong with your heart?

1	2	3	4	5	6	7	8	9	10
not at all									strongly believe

I3 Were you reassured by your exercise stress test?

1	2	3	4	5	6	7	8	9	10
not at all									completely reassured

I4 How accurate do you think the test was for identifying heart problems?

1	2	3	4	5	6	7	8	9	10
not at all									extremely accurate

I5 Do you believe you need further testing to find the cause of your chest discomfort?

1	2	3	4	5	6	7	8	9	10
not at all									definitely

Appendix K: Ethical Approval Letter

Ethics (Medical Research) Committee - Beaumont Hospital
Notification of ERC/IRB Approval

Investigator: Ms. Aisling Sheehan (RCSI)

REC reference: 09/17

Protocol Title: Non-Cardiac Chest Pain (NCCP): Physical and psychosocial factors influencing the maintenance of pain and health service use.

Ethics Committee Meeting Date: 27th February 2009

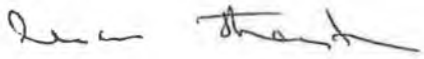
Final Approval Date: 27th March 2009

From: Ethics (Medical Research) Committee - Beaumont Hospital, Beaumont, Dublin 9

Documents Reviewed

Document and Date	Date Reviewed	Approved
Application Form, V2, 19/3/09, unsigned	27/3/09	Yes
Protocol, V2, 19/3/09	27/3/09	Yes
Prospective Study: Letter of Invitation, V2, 19/3/09	27/3/09	Yes
Retrospective Study: Letter informing about study, V2, 19/3/09	27/3/09	Yes
Telephone Call to Out-Patients (T1), no version number	27/3/09	Yes
In-Patient Information Leaflet, V2, 19/3/09	27/3/09	Yes
V3, 2/6/09	26/6/09*	Yes
Out-Patient Information Leaflet, V2, 19/3/09	27/3/09	Yes
V3, 2/6/09	26/6/09*	Yes
Pilot-Patient Information Leaflet, V1, 19/3/09	27/3/09	Yes
Consent Form, V2, 19/3/09	27/3/09	Yes
GP Letter, V1, 19/3/09	27/3/09	Yes

Questionnaires:		
Health Service Use (T1)	**27/3/09**	**Yes**
Reassurance and Perceptions (T2)	**27/3/09**	**Yes**
Health Service Use (T3)	**27/3/09**	**Yes**
Postal Questionnaire (T2), V1, 27/5/09	**26/6/09***	**Yes**
Health and Service use in patients referred for exercise stress testing	**27/3/09**	**Yes**
Health and Service use in patients 6 months after exercise stress testing V2, 19/3/09	**27/3/09**	**Yes**
Outcomes of Patients who don't attend exercise stress testing V2, 19/3/09	**27/3/09**	**Yes**
Interviews: Qualitative Interview Schedule, no version number	**27/3/09**	**Yes**
Protocol Amendment: #1, 2/6/09	**26/6/09***	**Yes**
CV: A. Sheahan	**27/3/09**	**Noted**



Professor Alice Stanton
ERC/IRB – Convenor's Signature
Approval # 2, dated 26th June 2009*

Appendix L: Consultant Depression Screening Letter

Website: www.beaumont.ie

Ospidéal Beaumont

BEAUMONT HOSPITAL
P. O. Box 1297 Beaumont Road Dublin 9
Telephone: 809 3000 / 837 7755 Facsimile: 837 6982

Dept of Cardiology
Date

Dear _____,

Re: Patient Name, Medical Record Number

This patient has been recruited to a study on patients referred for exercise stress testing. The research examines psychological distress in addition to symptoms, health service use and outcomes. Participants complete self-assessment standard questionnaires as part of the assessment.

This participant scored **highly** on a screening measure of **anxiety and depression** – the Hospital Anxiety and Depression Scales (HADS). Your patient scored above the threshold value of 11 for depression which indicates probable presence of a mood disorder. Although these scales are not diagnostic for depression or anxiety by themselves, it is recommended that a patient with high scores be investigated further. As part of the agreed protocol, the researcher will notify the participant that their scores appear high in this screening context. We recommend that you discuss this with your patient and make any appropriate referral you may deem necessary.

The study is being carried out as a doctoral thesis at Beaumont Hospital under the supervision of Dr Brendan McAdam, Consultant Cardiologist and in association with the Health Services Research Centre of the Royal College of Surgeons in Ireland (Professor Hannah McGee) and the Public Health Directorate, HSE (Dr Siobhán Jennings, Consultant in Public Health Medicine).

Should you have any queries, please contact the researcher Aisling Sheehan in the first instance at (01) 402 8586 / 087 9476366.

Yours sincerely,

Dr Brendan McAdam, MBBCh, MRCPI, MD Aisling Sheehan, BA

Appendix M: GP Depression Screening Letter

Website: www.beaumont.ie

Ospidéal Beaumont

BEAUMONT HOSPITAL
P. O. Box 1297 Beaumont Road Dublin 9
Telephone: 809 3000 / 837 7755 Facsimile: 837 6982

Department of Cardiology
Date

Research Study: Non-cardiac chest pain (NCCP): Physical and psychosocial factors influencing the maintenance of pain and health service use

NOTE: *This is not a discharge letter.*

Dear _____,

Re: Patient Name, Address

This patient has been recruited to a study on patients without a confirmed diagnosis of heart disease prior to exercise stress testing at Beaumont Hospital. It is aimed to identify targets for interventions to reduce both the personal and economic costs of non-specific chest pain. Participants complete self-assessment standard questionnaires as part of the assessment. Details of the study are summarised overleaf.

We contact you at this time as the patient's nominated doctor since this participant scored **highly** on a screening measure of **anxiety and depression** – the Hospital Anxiety and Depression Scales (HADS). Your patient scored above the threshold value of 11 for depression and anxiety which indicates probable presence of a mood disorder. Although these scales are not diagnostic for depression or anxiety by themselves, it is recommended that a patient with high scores be investigated further. As part of the agreed protocol, the researcher will notify the participant that their scores appear high in this screening context. We recommend that you discuss this with your patient and make any appropriate referral you may deem necessary.

The psychologist who works in the Cardiac Rehabilitation Programme at Beaumont Hospital, Jonathan Gallagher, has agreed to consider cognitive behaviour therapy for patients scoring highly on the HADS. If you think this may be helpful for your patient then you can email him at jonathangallagher@beaumont.ie or telephone him at (01) 8093262.

Should you have any queries, please contact the researcher Aisling Sheehan in the first instance at (01) 402 8586 / 087 9476366.

Yours sincerely,

Dr Brendan McAdam, MBBCh, MRCPI, MD

Aisling Sheehan, BA

Appendix N: Normality of Distribution

Table N.1 Skewness and kurtosis scores

Variables	Skewness (Std. Error)	Z-scores	Kurtosis (Std. Error)	Z-scores
Baseline				
Age	.038 (.201)	0.189	-.418 (.400)	-1.045
BPI Interference	.728 (.212)	3.43*	.049 (.420)	0.117
IntAvg	.728 (.212)	3.43*	-.049 (.420)	-0.117
Interference SqRT	-.359 (.212)	-1.693	-.289 (.420)	-0.688
Car Anxiety	-.092 (.206)	-0.447	-.545 (.410)	-1.329
CArAnxietyAvg	-.092 (.206)	-0.447	-.545 (.410)	-1.329
CAQ-Fear	.012 (.206)	.058	-.300 (.410)	-0.732
CAQ-Avoidance	.378 (.206)	1.835	-.540 (.408)	-1.324
CAQ-Attention	.530 (.206)	2.573	.511 (.408)	1.252
PHQ-15	.370 (.203)	1.823	-.679 (.404)	-1.681
HADS-A	.311 (.203)	1.532	-.379 (.404)	-0.938
HADS-D	.874 (.203)	4.305*	.384 (.404)	0.950
HADS-D SqRT	-.201 (.203)	-0.990	-.197 (.404)	-0.488
CP Frequency	-.152 (.209)	-0.727	-1.002 (.416)	-2.409
CP Severity	.335 (.207)	1.618	-.185 (.411)	-0.450
CP Duration	.493 (.208)	2.370	-1.028 (.413)	-2.489
CP Commenced	.264 (.206)	1.282	-.819 (.410)	-1.998
attCar	.490 (.219)	2.237	-1.071 (.435)	-2.462
attDig	.935 (.226)	4.137*	-.423 (.449)	-0.942
attDig SqRT	.655 (.226)	2.898	-1.065 (.449)	-2.372
attResp	.686 (.226)	3.035	-.972 (.449)	-2.165
attResp SqRT	.447 (.226)	1.978	-1.406 (.449)	-3.131
attPsych	.386 (.225)	1.716	-1.362 (.446)	-3.054
attPsych SqRT	.158 (.225)	0.702	-1.607 (.446)	-3.603*
IPQ 1	.664 (.209)	3.177	-.463 (.414)	-1.118
IPQ 2	.433 (.219)	1.977	-1.095 (.435)	-2.517
IPQ 3	.759 (.211)	3.597*	-.618 (.419)	-1.475
IPQ 3 Sqrt	-.046 (.211)	-0.218	-1.320 (.419)	3.150
IPQ 4	-.541 (.222)	-2.437	-.641 (.440)	-1.457
IPQ 5	.406 (.217)	1.871	-.491 (.430)	-1.142
IPQ 6	-.213 (.207)	-1.029	-.962 (.411)	-2.341
IPQ 7	.466 (.206)	2.262	-.780 (.410)	-1.902
IPQ 8	.026 (.208)	0.125	-.965 (.413)	-2.337
Time waiting for EST	-.231 (.209)	-1.105	-.912 (.414)	-2.203
Follow-up				
CP Frequency	.230 (.209)	1.100	-1.121 (.416)	2.695
CP Severity	.424 (.209)	2.029	-.692 (.416)	1.663
Reassurance	-.183 (.236)	-0.775	-.671 (.467)	1.437

Appendix O: Interview Schedule

Interview Guide

Can you describe to me the chest discomfort you get in your own words?

How does it feel? (Physically, Psychologically, Emotionally)
What happens when you get it?

How does it affect you (on a day-to-day basis)?

Changed life in any way?
How would you be different without it?
What about friends and family?
See yourself as ill?

Could you tell me about when it first started?

How long?
How did it come on?
Changed over time?

I'd now like you to think back to the first time you got medically help for your chest discomfort. Can you tell me about your experience with the health services from then to now?

Sent/waiting for tests?
Explanations?
Cardiac lens?
Doctors believing symptoms?

Were you given any explanation?

Getting results
How did you feel?
Other people give explanations?

Do you know why you are still getting it?

Heart?
Impact of not knowing / no diagnosis?
What causes?
Why not gone?

How do you manage it?

Medicine?
Self-help?
Reassurance-seeking?
Anything ease it?
Control

Is there any way, do you think, that health services can be improved?

Anything doctor said helpful? Unhelpful?
"Psych" label – seeing psychologist

Appendix P: Interview Themes

1. Kate's Interview

Relating to and negating real and presumed judgements

Accepting vs negating psychological attributions

P5	Symptoms preceded by worry
P6	Symptoms relaxed and calmed down – personifying symptoms as emotional responses
P9	Worsening by thinking about – blaming self
P9	Awareness that thinking provokes anxiety which worsens it
P10	Awareness cause more likely to be anxiety
P10	Diminishing as maybe 'just' panic attack
P10	Uncertainty over fit of panic since not in state of panic
P10	Trying to fit panic explanation – maybe type of panic attack
P10	Not fully convinced by panic explanation
P10	Awareness of power of mind on body and heart
P15	More certain of attribution to anxiety now
P18	Attribute sometimes to anxiety
P18	Realisation about anxiety
P20	Blaming self for letting it get to her

Relating to explanations

P2	Lack of exertion meant maybe not heart
P3	Healthier lifestyle meant attribution of anxiety
P4	Assumption panic since no explanation
P8	Dismiss as weight and anxiety
P10	Cause can be different – sometimes worry, sometimes over-exertion
P14	Didn't attribute to anxiety initially
P14	Lack of sense: anxiety without palps
P15	Related to anxiety explanation
P15	Became aware of anxiety once pointed out
P15	Lack of awareness of anxiety
P18	Attempting to fit attributions to possible explanations
P18	Unsure how to attribute
P18	Fitted explanation to own experience
P18	Deciphered anxiety as cause
P19	Related to explanation of anxiety
P19	Didn't relate brothers panic attacks to own symptoms
P19	Discussed panic attacks with brother and related

Disempowerment

Reality denied

P3 Questioning reality of symptoms
P3 Doubting self

Worthiness of care

P5 Questioning whether to seek help
P5 Embarrassment seeking help
P5 Not legitimate to seek help
P6 Discomfort seeking medical care – "not right" – unworthy
P7 Feeling unworthy of testing "shouldn't be here"
P7 Feeling out of place and unworthy – too young
P7 Felt wasting their time

Silence

P6 Monitored it on own
P11 Don't discuss with others now
P11 Won't draw attention to symptoms
P11 Deal with it on own
P16 Need to deal with on own
P17 Questioning worthiness of discussion

Negative emotional impact

P16 Partly angry no answers
P16 Feeling insignificant
P16 Feeling didn't matter
P16 Feeling unimportant

Search for empowerment in seeking information

P8 Sought confirmation of weight explanation but not answered
P9 Desire for answer from doctor
P15 Need for more info
P15 Desire to confirm hunch that weight to blame
P15 Need for more info so can manage
P16 Desire for referral for answers
P16 Need info on where to turn
P17 Desire to believe everything okay
P21 Desire to know what's wrong
P21 Desire for reassurance that attributions correct

Lack of control vs control

P2 Controlled exertion
P3 Lack of control over exertion at work
P5 Coped by taking deep breaths
P9 Controls by relaxing and taking deep breaths
P10 Lets go of discomfort with deep breathing

P12 More health conscious now
P12 Blaming self for not controlling weight better
P12 Stopped smoking to protect heart
P12 More aware of lifestyle choices
P12 More aware of keeping healthy
P13 Need to get stuck back into exercising
P13 Improvement in exercise but need to control weight problem
P17 More control over familiar feeling
P19 Need to control symptoms
P19 Onus on self to prevent symptoms
P19 Feeling out of control
P19 Questioning ability to control
P19 Careful with overexertion
P20 Monitoring exertion
P20 Less control over exertion at work
P20 Managed by easing back to work
P20 At home more control over symptoms
P20 Uncertainty over reaction of others anxiety provoking

Limbo

P8 Relief yet uncertainty
P8 Limbo between relief and uncertainty
P9 Mixed feelings: delight and uncertainty
P9 Left wondering – limbo
P15 Uncertainty over cause
P19 Uncertainty and worry

Power differential

P1 Undermining own attributions as less informed
P1 Unable to decipher whether heart attack
P9 Unable to ask for explanation
P9 Perhaps doctor not allowed to give own opinion??
P17 Confident they know more
P17 Unquestioning of doctors
P17 Awareness doctors can make mistakes
P17 Trust doctor is "right"

Empowerment

P8 Empowered to self-soothe
P8 More reassured to return to work
P8 Empowerment to live "normal" life
P10 Attribution to cause enables coping
P13 Knowledge been checked eases mind
P13 Doctors opinion nothing wrong reassuring
P13 Normal results enable self-soothing
P16 Reassured not serious

Medical Validation

Power over legitimisation of complaint

P8 Confidence in accuracy of tests
P14 Doctors opinion on cause valuable
P16 Dismissed as nothing wrong
P16 Dismissed because heart okay
P16 Only time felt dismissed

Need/lack of need for medical validation

P8 Bitter-sweetness of normal results
P13 Faith in tests
P17 Trust and faith in biomedicine

Attribution to medical or personal causes

P1 Attributes to fitness and weight
P3 Attribution of previous symptoms to anxiety
P5 Initially blamed smoking
P5 Attribution to anxiety
P10 Attributes to body over-working
P12 Attributing to weight and anxiety
P15 Guessing its over exertion
P18 Attribute to overexertion and weight
P18 Smoking not as big a factor as anxiety

Fear/worry about heart

Focus on heart

P1 Perception of heart coming out of chest
P1 Immediately think of heart
P12 Awareness of other causes than heart but chest and heart synonymous

Fear

P1 Frightening experience
P1 Fearful
P1 Anxiety-provoking
P1 Fear of collapsing
P2 Fear of activities inducing symptoms
P2 Context of lack of exertion frightening
P3 Fear of experiencing at work
P3 Fear of children
P6 Confusion and fear
P15 Still gets anxious that symptoms will happen
P20 Anxiety that work would provoke symptoms
P20 Return to work anxiety provoking in itself

Worry

P2 Afraid to do too much
P2 Afraid of over-exertion
P2 Conflict between desire to lose weight and fear of exercise
P3 Worry overdoing it
P4 Difference in pain worrying
P4 Worry about inheritance of family heart disease
P4 Murmur discovered when child played on mind
P8 Relief over normal results
P8 Reassured about ability to exercise
P8 Relief
P13 No more reluctance to exercise
P18 Uncertainty over benefit of exercise: improvement in health but not palpitations (confusion)
P20 Worried exertion at work would provoke symptoms
P20 Pre-empting symptoms at work

Inner struggles

Questioning (Is it mind (blame)? Is it normal? Confusion)

P1 Possibly other explanations – uncertainty
P1 Confusion over what's happening
P1 Provokes all sorts of thoughts
P1 Questioning why
P1 Question possibility when so young
P1 Question whether this unhealthy
P2 Questioned whether panic attack
P2 Questioning whether rushing around induced panic attack
P2 Questioning whether smoking to blame
P3 Questioning whether post-natal depression
P3 Worry its imagination
P3 Questioning health and lifestyle
P3 Everything goes through head
P5 Questioning whether panic or something serious
P5 Uncertainty about cause
P8 Questioning why
P8 Questioned whether post-natal depression
P9 Questions odd time
P10 Lots running through head
P10 Uncertainty why gets symptoms
P11 Severity of symptoms doesn't feel normal
P12 Questioning whether weight to blame
P16 Questioning what is it
P16 Questioning need for further help seeking
P17 Questioning whether imagination
P17 Questioning actuality of intensity of pain

P17 Questioning reality of symptoms
P18 Questioning whether imagining its worse
P18 Questioning whether bringing it on – to blame
P19 Question whether symptoms forever
P19 Questioning ability to cope
P20 Thoughts running through head

Accept and get on with it

P2 Doesn't affect now
P13 Belief that fine
P13 Mind at rest it's not a problem
P14 Put to bed – "that's that"
P17 Accepting everything okay due to desire to believe everything okay
P17 Accept it
P17 Put to bed "that's it"
P17 Gets on with it
P17 Ability to manage
P19 Need to come to terms with uncertainty
P19 Accepted it
P21 Gets on with it

Techniques to accept: Belittling, Normalising, Ridicule, Dismiss, Console

P1 Downplays
P5 Dismissing worry as silly
P7 Consoling self nothing wrong
P7 Consoling self too young
P8 Consoling self not to worry
P9 Have to put stop to thoughts as would drive you mad
P9 Downplaying symptoms
P9 Normalising
P9 Dismissing symptoms
P9 Takes mind off it
P9 Consoles self has been checked
P9 Distraction through music and talking
P9 Changes focus of mind to distract
P9 Copes by relaxing
P10 Tells self to relax
P10 Heart 'capable' of racing – normalising
P10 Assures self not harmful
P11 Reassures self it's normal
P11 Talks about another topic to distract
P12 Consoles self its normal process
P12 Tells self to relax and dismiss
P12 Ridicules worry about heart
P13 Consoles self has not harmed her before
P13 Dismisses it
P13 Always self-soothing

P13 Consoles self about normal results
P14 Accept as part of life
P15 Downplaying symptoms
P19 Downplaying – not like dealing with loss
P19 Downplays impact on life
P20 Eases anxiety by self-soothing
P20 Consoles self to relax and clam down
P20 Inner dialogue to console oneself
P21 Downplaying problem
P21 Relief not serious

Inadequacy to address psychosocial

Inadequate information?

P4 Lack of explanation whether panic
P4 Lack of help in distinguishing difference in attributions
P4 No definitive answer
P8 Told everything fine
P8 Disappointment with lack of explanation
P9 No answer
P13 Normal results reassures
P14 Lack of information
P14 Could have given more info
P14 Downplays importance of getting more info
P14 Desires for more information
P14 Info on cause desired
P16 Told nothing wrong insufficient
P16 Defending doctors inadequate info due to lack of time
P21 Acceptance no definitive answer
P21 More info on thinking main thing

Adequacy of care?

P6 Lack of long wait for hospital appointment
P8 "grand" – suggests not fully resolved
P14 Staff acceptable – "grand"
P14 Questions whether should have discussed weight – not comprehensive?
P15 Satisfied with treatment
P15 Questioning whether should have been referred (tentative questioning)
P15 Questioning need for referral to dietician (To deal with perceived cause)

Deciding to seek help

Futility

P14 No need to seek further help

Defending decision to seek help

P5 Worsening of symptoms meant could not dismiss
P6 Mentioned to doctor in passing
P7 Justifying tests with potential seriousness of symptoms
P7 Family history justified testing
P7 Consoled self testing was important
P17 Difference in symptoms prompts help seeking

Influence of others

P1 Dad's heart problem intrudes on thoughts
P4 Dad's angina played on mind
P4 Parents reassuring her it's panic
P6 Mother encouraged discussion with GP
P6 Mothers worry something wrong pressured her
P11 Mother would pressure to get checked
P11 Mother would not think its right or normal to suffer
P11 Partner dismisses it
P11 Partner discourages worry
P11 Avoiding mother worrying by concealing
P12 Mother would force her to seek help
P12 Fathers heart problems influences lifestyle choices
P14 Family member suggested attribute to anxiety
P15 Family advised its anxiety
P18 Mother suggested relationship to brothers panic attacks
P20 Confided with colleagues about symptoms to prepare them
P20 Worried how would handle symptoms in front of others

Fear/worry

P7 Nervous about stress test
P7 Bit nervous about tests
P7 Nervous would be unable for stress test
P8 Tests daunting

Extra

P1 Context: when not doing a lot
P5 Context: when relaxing
P8 "foreign" doctor

2. John's Interview

Relating to and negating real and presumed judgements

Accepting vs negating psychological attributions

P1 Awareness of link between thoughts and symptoms
P1 Lessened due to lack of worry
P5 Certain not in head
P6 Preserving identity as laid back and not stressed
P6 Not stress but thinking
P10 Accepting of stress explanation
P10 Normalising trigger of stress
P10 Insight into delay of impact of stress on body
P10 Stress worsened symptoms previously
P10 Previously induced fear which worsened it
P13 Thinking worsened it
P14 Related to explanation of stress/run down
P15 Awareness perception of self can be wrong
P15 Insight that may not be aware that stressed
P19 Attributes sisters palps to grief and stress
P19 Attributes to stress: sisters palps stopped once grief period finished
P19 Likens symptoms to grieving process – emotional response that fades
P20 Awareness of impact of stress on mind and body
P20 Sister's palps attributed to state of mind
P20 Likens palps to grieving process – emotional impact on body that resolves with time

Relating to offered explanations

P1 Attributes to stress
P10 Relating to suggested lifestyle triggers
P10 Info made sense and related to it
P10 Attributing to stress at work
P10 Context: relaxing – delayed impact
P14 Accepting of explanations
P14 Dismissing as stress/run down
P14 Explanations make sense
P14 Ability to attribute triggers to symptoms
P15 Ability to relate to triggers offered reassuring
P26 Relating to knowledge empowers

Disempowerment vs Empowerment

Reality denied

P5 Felt maybe its in head
P13 Illegitimacy of symptoms: "it's nothing"
P27 Nothing wrong – not illness

Worthiness of care

P26 Embarrassment over seeking help

Silence

P18 Non-significance: comical to reveal to others
P18 Kept hidden from others: not worthy of discussing
P18 Lack of significance to others
P18 Not worthy of discussing

Negative emotional impact

P6 Overwhelmed by uncertainty
P7 Hardship of uncertainty

Search for empowerment in seeking information

P4 Empowerment of knowledge to ease mind and cope
P4 More transparency with immediate results
P4 Looking forward to tests and answers (Feeling of progress)
P5 Uncertainty whether something wrong with heart
P6 Lack of impartment of knowledge causing worry
P6 Unable to judge outcome of test
P7 Need for prompt answer
P7 Lack of understanding during test
P8 Desire for more info
P8 Knowledge empowers
P9 Lack of understanding
P9 Hardship of not knowing
P9 Empowerment of knowledge
P9 Unable to ask right questions and get good info
P9 Disempowerment due to knowledge differential
P10 Previous uncertainty about resolving
P16 Overwhelming nature of consultations
P20 Preparation for tests by discussing with sisters
P20 Interest in how tests worked
P21 Desire to understand process
P21 Empowerment of knowledge
P21 Understanding puts mind at ease
P22 Seeking understanding of test
P22 Judging reactions to decipher information
P23 Need to know outcome
P24 Easier to move on with results
P24 Need for answer either way
P24 Knowledge empowers you to act on it
P25 Knowledge is key
P28 Explanation most important
P28 Uncertainty the problem
P29 Unanswered questions the problem
P30 Need for information

Lack of control vs control

P1 Unpredictability
P2 Uncertainty and lack of control
P10 Acceptance out of his control
P15 Randomness of symptoms – lack of control
P17 Previous lack of control
P19 Uncontrollable
P20 Randomness of occurrence

Limbo

P4 Tests – added uncertainty and concern
P4 Waiting worsens issue
P4 Long waiting times
P4 Process long-winded
P5 Waiting period time to ruminate/worry
P5 Hardest part waiting
P5 Leaving hospital with uncertainty
P6 Hopeful but uncertainty
P6 Vague terms to describe test outcomes "fine" "grand"
P7 Too much time to think
P7 Waiting makes worse
P7 Series of apps disrupt 'grieving process' – unable to forget
P9 Apps induce thoughts
P21 Uncertainty causes constant thoughts
P22 Not knowing worsens problem
P23 Unable to move on due to wait for results
P23 Waiting times offputting
P23 Waiting hard
P24 Revisit thoughts on approach of apps
P25 Disempowerment "sitting there waiting"
P26 Letters reminders
P26 Living with possibility of heart defect
P27 Testing commencement of limo and uncertainty

Power differential

P7 Strained relationship with staff due to power differential
P7 Control of staff over knowledge
P8 Contrived nature of conversation with staff
P16 Difficulty in processing info from doctor renders questioning difficult
P21 Disempowerment: results "taken away from you"
P21 Doctor controlling of test results
P22 Dependence on doctor for understanding
P22 Control of doctor over imparting of knowledge
P22 Knowledge differential unfair
P27 Power differential GP and patient
P28 GP controlled knowledge and exerted power
P28 Doctor as king old-fashioned

P28 Previous GP king – power
P30 Lack of ownership over body
P30 Right to know what's happening
P30 Disempowered

Empowerment

P10 Increased awareness of triggers
P10 Ability to decipher triggers now (empowerment)
P10 Determining possible mundane triggers
P10 Empowered to controls symptoms
P3 Control over impact
P10 Assured can control its impact
P10 Controlling emotions to diminish impact
P10 Coping by breathing
P10 Sense of master over coping
P11 Control of heart by leading healthy lifestyle
P12 Disapproving of leading unhealthy lifestyle
P12 Admiration for fitness in elderly
P12 Importance of leading healthy lifestyle
P15 Healthier diet improved symptoms – control
P15 Info on triggers empowers
P17 Empowerment to control now
P18 Control over interference
P18 Coping mechanism: breathing
P1 Reassured by normal tests
P1 Normal test results reassuring
P2 Reassurance
P24 Normal results eased mind
P24 Test results info eased mind
P24 Reassured about heart getting results
P26 Empowerment to live "normal life"

Medical Validation

Power over legitimisation of complaint

P9 Control over legitimate illness
P9 No answer because nothing wrong
P16 Need for medical reassurance
P18 No legitimate illness
P28 Sending for tests medicalised – it became problem

Desire for answer overrides desire to be well

P21 Not knowing worse than having disease
P21 Possibility of cancer worse than having cancer
P25 Equal relief to hearing have heart defect
P25 Not knowing worse than knowing about disease

Need/lack of need for medical validation

P21 Diagnosis enables action and coping

Attribution to medical or personal causes

P13 To blame for worsening: "forced it upon myself"
P14 Attributes to leaky gut
P15 Underlying trigger sometimes
P20 Blaming self: over-stressed about normal experience which worsened it
P29 Blaming personality for worry

Medical process fear-inducing

P3 Doctors response of sending for tests induced fear
P3 Magnitude of heart test scary
P4 Non-mundane, serious test
P4 Scary vs not scary
P4 Lack of urgency
P6 Confusion over reason to remain after test – worry something wrong
P7 Periods of forgetting disrupted by periods of consuming thoughts
P26 Questioning functioning of heart naturally worrying
P27 Tests fear-inducing

Fear/worry about heart

Focus on heart

P1 Describes in terms of heart "big heart beat"
P13 Attuned to heart sensations at night
P13 Intrusion of heart beat when attempting to relax
P13 Attuned to changes in heart beat rate
P19 Focus on heart disrupted sleep

Fear

P1 Initially frightening
P1 Lack of understanding frightening
P2 Fear previously
P2 Feeling of anxiety in stomach
P2 Anxiety
P2 Considers fear immature response
P2 Fear of heart problem
P3 Fear of potential heart problem
P11 Induced fear of re-occurrence previously

Worry

P1 Worry greater before results
P2 Anxiety over lack of control
P2 Forget about once ceases
P2 Worry previously

P5 Incessant worry waiting for results
P10 Stress pointless
P13 Concern that had abnormal heart rate
P13 Concern about perception of elevated heart rate
P24 Questioning in mind repetitive
P27 Necessity of heart makes worse
P27 Overwhelming nature of heart tests
P27 Huge significance of tests: potentially life-threatening
P27 No emotional impact now
P27 Importance of heart amplifies seriousness of testing

Inner struggles

Questioning (Is it mind (blame)? Is it normal? Confusion)

P4 Associates heart test with older people
P4 Confusion due to being young
P6 Constant questioning with no answers
P6 Questioning/uncertainty worsens stress
P20 Questioning normality of his symptoms
P24 Questioning whether mental
P24 Questioning whether normal process in body
P29 Questioning whether nature of self as questioning is immature

Questioning adequacy of tests, medication & explanations

P5 Uncertainty over tests due to need for occurrence of symptoms

Accept and get on with it

P1 Acceptance "it happens"
P1 Doesn't worry now
P1 Gets over it
P2 Lack of care now
P2 Procedure for coping: stop and take deep breath
P2 Coping: breathes to clear mind
P3 Consciously deals with each symptom – acknowledges them & clears head
P3 Gets on with it
P4 Reminding to prevent forgetting tests
P4 Need to accept waiting time
P9 Accepting of lack of answers
P9 Forgotten now
P11 Lack of care now
P11 Acceptance
P19 Acceptance part of life
P26 Lack of significance now
P29 Get on with it
P29 Need to accept and live with uncertainty
P29 Lack of significance now

P29 Futility in thinking about since outside of control

Techniques to accept: Belittling, Normalising, Ridicule, Dismiss, Console

P1 Belittling "just"
P1 Downplaying
P1 Forget about it
P1 Normalising
P1 Awareness
P1 Doesn't allow himself to think about it
P1 Non-significant event
P3 Downplaying impact
P3 Lack of intrusion on life
P7 Downplaying problem (embarrassment?)
P7 Belittling problem
P7 Not totally consuming
P7 Likens to grieving process – consuming thoughts lessen
P9 Keen to portray as forgotten issue (acceptance, downplaying)
P11 Downplaying impact
P11 Nonchalant about symptoms now
P17 Downplaying symptoms
P17 Acceptance as normal and non-significant
P17 Reassures others nothing to worry about (Downplays)
P18 Lack of interference
P18 Normalising
P18 Pales in significance to leaky gut
P19 Lack of significance and importance
P19 Lack of interference
P26 Put to back of mind (repress?)
P26 Berates himself for worrying
P27 Normalising
P27 Dismisses as "just another thing"
P29 Acceptance of uncertainty associated with increased maturity
P29 Ridiculing his inner dialogue
P29 Berating worry as immature response
P29 Ridiculing his worry
P29 Dismisses own thoughts
P29 Scolds himself for worrying
P30 Doesn't dwell on it – repress?
P33 Downplaying its effect on him due to his youth

<u>Adequacy vs Inadequacy to address psychosocial</u>

Dismissive

P5 Dismissed after test
P27 Previous GP dismissive and no info

Medical uncertainty

P9 Sought explanation but none

Inadequate information?

P7 Lack of communication during tests
P7 Rudeness of one staff member "grunted"
P7 Defending staff
P7 Understanding staff not allowed reveal
P7 Concealment of staff
P8 Questions unanswered
P5 Expectant of result after test
P8 Expectant of more information
P8 Defends staffs lack of info imparted
P9 Suggestions of lifestyle triggers
P9 Attempts to explain by consultants
P13 Doctor reassuring about heart – presented evidence to contrary
P13 Accepting of "nothing wrong" answer
P13 Feeling of resoling unanswered questions
P13 Doctors offered explanations about possible triggers – reassuring
P15 Acknowledges standard answers
P22 Failure to impart knowledge frustrating
P22 Need for transparency
P23 Acknowledges no news probably good news
P24 Possibility of training technicians to give results
P24 Unacceptable wait for results
P24 Purpose of echo test explained
P25 Awareness of individual preference for info
P30 Defending staffs lack of information
P31 Option to get more information helpful
P31 A couple of sentence sufficient to improve experience
P33 Lack of impartment of knowledge unacceptable

Adequacy of care

P4 Inadequacy of public health service
P5 Doctor comprehensive listening to heart
P5 Staff lovely and supportive
P7 Accepting of public/private differential
P13 Consistent information
P22 Acceptance of waiting for tests in public system
P22 No choice but to accept waiting times
P22 Senselessness of waiting for results
P22 Reasonable to expect immediate results
P22 Constant queues
P23 Lucky to get test 6 months quicker
P23 Disbelief over waiting times for echo
P23 Questioning adequacy of waiting times
P23 Discrepancy of waiting times between hospitals

P24 Sent for confirmatory tests
P24 Comprehensive testing
P24 Doctor reassuring
P28 Blaming public health service for length of process
P32 Acceptance about health service delay
P32 Health services inadequate
P32 Government failed to improve services by wasting money
P33 Acceptance about waiting times due to economic circumstances
P33 Incredulous about waiting times
P33 Blame lies with system
P33 Unfairness of waiting

Support?

P4 Follow up visit offered
P8 Staff putting him at ease
P8 Defending staffs niceness
P8 Appreciative of staffs niceness
P8 Onus on staff to be nice
P13 Doctor put mind at ease
P14 Not dismissive – follow up was offered

Deciding to seek help

Futility

P25 Futility in asking for picture of echo

Defending decision to seek help

P19 Increase in symptoms prompted doctors visit
P19 Increase in symptoms worrying (vicious cycle)
P21 Value in seeking medical care to ease mind
P28 Doctor visits only when necessary

Influence of others

P1 Ignored until pressure of others
P1 Pressure of others to get checked
P1 Reaction of another spurred investigation
P2 Awareness of others when experiencing
P3 Initial symptoms not memorable
P3 Lived with 2 years before seeking help
P15 Parents discouraged worry
P15 Parents dismissive of symptoms
P15 Parents attempts to be reassuring
P16 Confidence of parents not convincing enough
P18 Lack of reaction when parents hear of persistence
P26 Attempts by family to reassure about interventions for heart

Fear/worry

P2	Associates hospital with death
P2	Fear of staying in hospital
P2	Apprehensive to get checked
P3	Worry and fear of needing hospital stay
P3	Constant worry prompted medical healthcare-seeking
P19	Does not pre-empt or worry about

Extra

P1	Improvement now
P1	Context: doesn't wake at night
P1	Context: mulling around and relaxed
P17	Symptoms improved
P26	Difficulty in remembering

3. Alison's Interview

Relating to and negating real and presumed judgements

	Real and presumed judgement
P25	Embarrassment over perceived appearance of madness talking to herself
P25	Being judged as crazy
P29	Fear of looking like had mental illness
P30	Fear of looking mentally ill – all looked same
P30	Huge effort into appearance to avoid looking like "them"
P30	Fear of being perceived as mentally ill
P36	Pre-empting assumption of anxiety

	Accepting vs negating psychological attributions
P1	Anxiety probable explanation – uncertainty
P2	"mad" sensation – using emotional term to describe physical sensation
P2	Blaming self: probably go into panic
P2	Stressful life situation
P2	Stress levels rose due to life circumstances
P4	Head won't let her unwind
P4	Being tortured for attempting to relax – persecuted/victimised
P5	Attributing chest pain to panic attack
P8	Something in head needed to get out
P10	Increased stress to blame for panic
P18	Symptoms depend on stress levels
P19	Puts symptoms down to anxiety
P21	Attributed sickness to aftermath of panic attack
P25	Understanding of body's reaction – adrenalin and fight or flight response
P29	Thought had mental illness
P29	Now believes not mental illness but learned behaviour
P29	If mad then wouldn't feel pain: separating self from being mad
P29	Distancing self from mental illness: "they"
P29	Important that anxiety distinct from mental illness
P30	Stigma attached to mental illness
P30	Detaching self from mental illness: "these people"
P30	Avoiding stigma
P30	Freaked out holding hands like resident of mental hospital
P32	"They" suffered from depression – distancing self from depression
P32	Keen not to be labelled as depressed
P33	Stress of managing niece brought on anxiety
P34	Very stressful life circumstances
P36	Separation of anxiety and sickness
P36	Dismissing as anxiety
P37	Accepting of anxiety if felt properly investigated
P37	Possibility its not anxiety
P41	Awareness gastric trouble not diagnosed gastroenteritis but anxiety
P41	Anxiety when on holiday – unable to eat

P41 Gastric trouble ended once knew going home
P49 "mad" tablets – derogatory
P50 Dismisses and belittles people who say they feel a little down
P50 Tells people to snap out of it

Relating to offered explanations

P4 Ability to accept anxiety due to book's explanation
P22 Relating to symptoms of anxiety book described
P24 Only viable explanation is that offered by CBT programme
P31 Immediately related to symptoms described in CVT book for anxiety
P31 Reassuring to know others have symptoms
P32 Book explained anxiety brought on depression
P38 Related to spasms in bowel explanation
P39 Happy with hormonal explanation – not dismissive

Disempowerment

Reality denied

P7 Doctor reassured her didn't need meds but to relax and calm down
P7 Said nothing: unsure of doctors opinion? (symptoms so severe?)
P8 Denying reality – snap out of it

Worthiness of care

P6 Unimportant – hours before someone "would" see me (choosing to ignore)
P7 Unworthy of hospital
P7 Doctor questioning need for her to return
P19 No need for doctor since anxiety
P29 Reached point of suicide before mental health services offered
P35 Discrimination of medical staff based on appearance
P35 Patients blamed for illness – fat and drunk therefore dismissed
P42 Anxiety should not discriminate against medical investigation

Silence

P3 Tries to explain but no-one understands
P9 Need for husbands support
P9 No-one understands
P9 Nobody understands unless experienced it themselves
P22 Can only understand if experience it
P22 Never spoke to someone with same symptoms
P24 Tells nobody when has panic attack
P24 Futility in speaking about it
P36 Deals with in on own

Hopeless

P10 Desperation and helplessness – what am I going to do
P20 Desperation – crying

P20 Feels like panic will last forever

Search for empowerment in seeking information

P14 Natural to want to know why symptoms are happening
P17 Questioned whether thyroid causing problems
P20 Clueless why still gets symptoms
P31 Had to seek information herself
P31 Search for understanding
P32 Searched on internet for understanding
P36 Need to know what's causing symptoms

Lack of control vs control

P1 Lack of control – might go away
P1 Sudden and unexpected – lack of control
P1 Subsides eventually
P1 Pain random
P2 Need to relax breathing to control it
P2 Distracting eases pain
P10 Never felt "normal" for years
P15 Justifying smoking due to stress
P15 Defensive about lifestyle behaviour – not a drinker
P15 Conflict: when drunk only time feels good but alcohol fear inducing
P18 Desire to be healthy
P18 Struggle to quit smoking
P18 Stress levels out of her control
P18 Onus on self to keep heart healthy
P18 Control of smoking when pregnant
P19 Knows anxiety will subside
P19 Taking tapes out again feels like step back
P19 Associates listening to tapes with horrible time
P19 Doesn't want to go back to where was
P21 Mind won't let me have peace – mind controlling her
P24 Attempts to control next attack better
P25 No control over onset of panic – spontaneous
P26 Not enough willpower to quit smoking
P28 Justifying dependence on cigarettes to cope with stress
P31 Self only person can help symptoms
P31 Onus on self to control
P40 Bought loads of meds for anxiety on holiday – feeling out of control
P41 Controlling drink and sleep to cope on holidays
P41 Only drinks decaf now – control
P42 Need to monitor self to keep in control

Limbo

P16 Thought would be dead before echo
P20 Feel like stuck in past
P43 Waiting increases anxiety

Power differential

P8 Begged doctor for medication
P8 Begged doctor before referral for mental health clinic
P12 Physically held down for gastroscopy – power
P12 Embarrassment over hysterical reaction (power)
P13 Felt really small
P13 Shameful exit from hospital
P43 Doctor scolded her for not finishing meds
P45 Importance of doctor's approach and demeanour

Empowerment

P18 Relieved when told heart was okay
P18 Relaxed a bit when told heart okay
P43 Reassured nothing wrong with brain

Medical Validation

Power over legitimisation of complaint

P10 Having tests done gave hope would be okay once tests completed
P17 Thyroid explanation dismissed
P37 Worry if something wrong won't be detected

Validation

P17 High heart rate validated by doctor and medicated

Desire for answer overrides desire to be well

P9 Desire for test to show what's happening
P11 Kept saying needed echo as most important – maintained hope
P11 Hopeful echo would give answers
P17 Desire to get echo results since most important

Need/lack of need for medical validation

P37 Need to be told what's wrong

Attribution to medical or personal causes

P1 Attributes to wind once belches
P17 Read thyroid put strain on heart
P39 Gastric trouble possibly hormonal
P43 Perception that sinus blocked putting pressure on brain

Medical process fear-inducing

P16 Thought would die on stress test

Fear/worry about heart

Focus on heart

P1 Attribute to heart attack in moment
P3 Feeling of shocks coming from heart
P5 Expected heart attack
P7 Feeling of blood rooting through veins of heart

Fear

P1 Feel going to die
P2 Panic takes over
P2 Always panics
P5 Terrified was dying
P5 Fear increasing
P9 Eating uncontrollably due to fear of not being able to eat again
P10 Feeling of dying
P13 Fearful of lump near heart
P15 Terrified of activities which may bring on symptoms
P15 Terrified of physical activities
P16 Terrified of everything
P16 Fear of dying from everything
P16 Avoidant of everything due to fear of death
P16 Avoidant behaviour has improved
P17 Every little extra beat terrifying
P17 Terrified of sensations in chest
P17 Avoided exercise
P22 Fear of fear itself
P25 Fear of collapsing in public
P25 Frightened when occurs
P26 Fear of dying in front of kids
P28 Terrified if anything bad happens to kids
P38 Fear of side effects of tablets
P48 Realisation fear of dying in front of children due to seeing mother die

Worry

P3 Sensations anxiety provoking
P15 Worried what health will be like in future?
P17 Coming to terms that heart okay
P17 Had been extremely worried about heart
P17 Fast heart rate not worrying until panic attacks
P28 Can't cope with seeing kids hurt
P37 Will be dead before given answer
P43 Worried something wrong with brain

Inner struggles

Questioning (Is it mind (blame)? Is it normal? Confusion)

P9 Questioning whether illness is aftermath of anxiety
P21 Questions whether devil in her as unable to stay in church
P31 Fearful something serious wrong due to lack of understanding
P36 Can't distinguish if sick or anxious
P36 Questioning whether symptoms are all anxiety
P36 Has to live life questioning
P50 Senseless getting symptoms when left alone
P50 "mad" – confusing

Questioning adequacy of tests, medication & explanations

P8 Antidepressants worsened anxiety
P9 Taking tablets: more out of control
P18 Conflict: relief but what if?
P20 Questioning whether need to start meds again
P20 Meds make her zombie
P20 Quit meds due to side effects
P20 Rebound anxiety when quit meds
P23 Told to talk about everything in therapy
P23 Unable to discuss everything in therapy
P23 Gave support to others in group support
P23 Doing psychologist's job in group support
P23 Taking on everyone else's problems wasn't helpful
P23 Causing worry about others
P23 Discomfort being in mental heath services
P26 Tablets for brain wrong
P26 Tablets for mind mask symptoms and don't deal with them
P26 When stop taking tablets, hits with bang
P26 Back to square one when cease tablets
P26 Perseverance and strong will enabled quitting meds
P30 Futility of giving pills
P42 Control by keeping on tablets
P42 Tablets not the solution
P42 Tablets disempowering – zombie and unable to function
P43 Unable to finish due to bad side effects of antibiotics
P48 Would have been better if had CBT
P48 Would have been better with help in hospital

Accept and get on with it

P20 Accepts symptoms
P36 Has to get on with it
P36 Not legitimate to stay in bed – needs to do housework
P37 No choice but to put up with it
P43 No choice but to put up with it
P44 No choice but to put up with it

Techniques to accept: Belittling, Normalising, Ridicule, Dismiss, Console

P16 Consoling self was fine
P21 Self consoles will go away
P23 Tells self is strong and has moved on
P24 Reassured self didn't die
P25 Self speak: not going to let it take over her
P25 Consoles self will not collapse/die
P25 Consoles self only panic (downplaying)
P25 Assures self can cope
P25 Counts in head to distract
P25 Belittling self: "stupid cow"
P36 Coping mechanisms like breathing
P36 Consoles self can get through it

Dramatising

P2 Horrible feeling
P6 Symptoms deteriorated and unable to eat
P15 Should be healthier for age
P15 Expecting to deteriorate further with age
P15 Mother health complains but able to do activities (comparison: dramatising own situation)
P15 Pathetic – can't even kick ball with kids
P15 Physical ability not concordant with expectations for age
P20 Dramatising: wouldn't wish on worst enemy
P20 Sensations drive her mad
P21 Still horrible feeling
P22 Worst feeling ever
P22 If had cancer could understand
P22 Worse than having cancer
P22 Horrendous
P22 Worst symptoms possible

Coping

P1 Coping: rubs pain
P2 Attempts to take mind off it
P2 Worse if sits with it
P2 Need to move around and do something
P2 Distracts by moving around
P8 Unable to cope anymore – wanted to end it
P8 Unable to live anymore
P9 Easier to cope now though
P19 Keeps busy to avoid panic attack
P19 Able to cope with it
P19 Took up hobby of painting on advice of back
P19 Kept mind occupied and was fine
P20 Unable to dismiss sensations previously
P20 Changed way attributes symptoms

P21 Difficulty in retraining brain
P23 Programme advised to let go to past
P23 Tries to leave things in past
P23 Oppresses thoughts of past
P23 Talking about it doesn't' allow her to move on
P23 Felt better when stopped going to groups – wasn't constantly in past
P24 Ability to cope on own
P24 Gets through it
P24 Previously ran home to bed due to lack of understanding
P25 Understands what's happening
P25 Talking to self to ease fears
P26 Techniques to cope not enough
P26 If there was tablets to control it would take it
P26 Struggles through housework and feels great when finished
P26 Now able to be left alone without panic attack
P27 Inability to cope with chaos of household
P45 Pride overcame fear and had procedure (coil)
P48 Difficulty in coping on own due to family and everyday stressors
P49 Tries to cope without antidepressants
P49 Feels okay when kept busy

Inadequacy to address psychosocial

Dismissive

P6 Abandoned in hospital for hours "leaving me here"
P6 Dismissed – left on chair crying
P7 Dismissed – go home
P8 When said going to kill herself finally given advice
P36 Doctor dismisses everything as anxiety
P37 Unfair to dismiss as anxiety
P37 Everything dismissed as anxiety
P37 Branded as anxious
P37 Not taken seriously
P37 Bothers her not taken seriously
P37 Chest pain dismissed as anxiety or muscle pain
P39 Not dismissed as anxiety when doctors not aware of her anxiety
P39 Taken seriously and got scan and medication
P42 Pain should be investigated and not dismissed

Medical uncertainty

P31 Nobody understood
P38 Given tablets for IBS at another hospital
P38 GP dismissed IBS explanation
P38 Conflict in doctors' opinions
P38 Frustration with conflicting information

Inadequate information?

P6 No explanation for chest pain
P7 Explanation of vertigo
P16 No results
P16 Consoling self no news is good news
P17 Disbelief over lack of answers in hospital
P17 Technician said everything perfect on echo
P23 Given explanation of anxiety and bereavement
P31 Nobody told her how to cope
P31 Person who's had symptoms best person to offer explanation
P43 Told everything was fine

Adequacy of care?

P7 Doctor told her dosage was too high for vertigo – difference in opinion/treatments
P8 No help
P8 Expected to be seen straight away but had to wait
P9 Despite psychological help hasn't gone
P10 Wait not too long for cardiologist
P11 Justifying fear of being put to sleep and gastroscopy
P12 Attempted to comply with gastroscopy but hysterical
P12 Staff cold and dismissive when unable to do gastroscopy
P12 Need for understanding and comfort but dismissed
P13 Lack of assistance
P13 Totally dismissed
P13 Staff could have given her another chance
P16 Long wait for echo
P18 Needs help to quit smoking
P22 Psychiatrists just want to give meds
P29 Hospital should have given support for anxiety
P29 Someone should have explained symptoms in hospital
P29 Should not have needed to deteriorate until offered help
P29 Fear of going to mental health services
P30 Hospital should have services instead of need for mental health services
P30 Shame in attending mental health services
P30 Shouldn't have got so sick
P30 Sickness preventable
P30 Treatment terrible
P32 Support groups unhelpful since no-one had same symptoms
P32 Inappropriate group support since not depressed
P32 Could relate to people with depression
P32 Took on everyone's symptoms
P32 Helpful not to be thinking of self – distraction
P34 Story of inadequacy: no help for niece – abandoned by services
P34 Social services inadequate and wrong
P35 Story of inadequacy: sister in law treated inhumanely and blames hospital for her death

P36 Doctors all unhelpful
P36 No support
P37 No support/care offered
P42 Nobody giving help
P42 Not fair to have to pay for CBT
P42 CBT should be available in hospital
P42 Questioning why no services in hospital
P42 CBT should be in hospital
P42 Shouldn't need to go to mental hospital
P42 Value of CBT for depression also
P43 Unable to wait for brain scan so paid for it
P43 Speediness of service when pay
P43 Doctor unable to help
P44 Health system crazy
P44 Unacceptable waiting times – frustration
P45 Story of inadequacy: doctor terrifying child about surgery – anger
P45 Story of adequacy: dentists' fantastic, supportive approach to child
P46 Story of adequacy: more supportive approach able to get through procedure
P47 Story of inadequacy – broke public bone during childbirth – should have had c-section
P49 Story of inadequacy: husband still suffering from operation years ago
P49 Pharmaceutical companies out to make money
P49 Antidepressants money-making scheme
P50 Doesn't' want to end up in mental hospital
P50 Would have ended up in mental hospital in past
P50 Horrified at treatment of people with mental illness in past
P50 Deception of doctors to patients with mental illness in past
P50 Warns people against anti-depressants

Deciding to seek help

Futility

P6 Futility – nothing they can do
P22 Lack of understanding from doctors
P24 Futility in seeking help
P24 Nothing anyone can do
P26 Tablets can't control it
P26 Need for tablets to help me (contradiction)
P26 Pride in coming off tablets
P36 Had to help herself
P36 Futility in going to GP – knows what will say
P37 Futility in seeing doctor

Hope of alternative medicine

P4 Spent all mother's inheritance on alternative therapies
P4 Tried healers and acupuncture

P4 Last resort CBT programme for anxiety and panic
P4 Book reassured her
P4 Without book would be kicking down door of hospital
P19 Tapes helped to retrain brain
P21 Tapes explained symptoms
P21 Tapes helped retrain brain
P30 Book and cds changed life
P32 Lost without CBT programme
P42 Feels benefits of CBT when time to practice

Defending decision to seek help

P5 Attempted to stay focused until ambulance – dependence on healthcare
P6 Justifying need for return to hospital: dramatising
P6 Desperation for hospital – begged husband
P7 Begged them to keep her in hospital
P7 Desperate for medical care
P7 Ended up at D-Doc – out of her control
P8 Continually sought help from mental hospital
P9 Desire for brain surgery for answers
P18 Needed tests to rule out possibility of strain on heart
P22 Can handle without needing hospital

Influence of others

P5 Family called ambulance due to her terrifying reaction
P10 Friend died of cancer at young age
P10 Daughter laughs at her hysteria (Family dismissive and belittling)
P15 Mother died of cancer
P17 Didn't want to hear about others with heart attacks – fear inducing
P20 Husband reassuring and comforting
P24 Tells husband so he understands why she can't do what she could before

Impact on life

P3 Unable to sleep with symptoms
P15 Unable to do chores did before
P15 Big impact on life
P21 Demonstrating significance of not being able to bring kids to school
P24 Husband expects return to old self
P24 Husband feels lost and out of loop
P28 Husband frustrated can't leave her alone
P40 Pretending to enjoy self on holidays
P40 Putting on act
P43 Suffered not being able to have meds due to interactions

Extra:

P3 Difficult to describe symptoms

P4	Context: attempting to relax
P18	Futility in smoking as don't enjoy
P21	School yard anxiety provoking
P21	Peace at church but then ill at church (contradiction)
P33	Feeling pressure to help others
P33	Questioning self why she's helping niece
P34	Struggling to help niece
P47	Stopped having children due to mother death
P47	Unable to accept mother's death
P47	Need to accept inevitability of death

4. Brian's Interview

Relating to and negating real and presumed judgements

Real and presumed judgement

P1 More comfortable discussing asthma than unexplainable symptoms
P3 GP thought appeared anxious
P12 Doctor attributed to anxiety
P19 Judgement that nothing wrong by GP since appears healthy
P20 Doctor attributes to anxiety/depression
P22 GP felt showing signs of anxiety
P22 GP explained symptoms as anxiety

Accepting vs negating psychological attributions

P3 Perceived to be being healthy by walking and eating little (normalising symptom of anxiety)
P4 Acceptance of anxiety medication
P9 Trauma of losing wife in 2002
P12 Not accepting of anxiety explanation
P12 Inevitability of anxiety if body not right
P16 Negating attribution of bad sleep to anxiety
P20 "Whatever" – dismissive of anxiety/depression explanation
P20 Accepting has symptoms of anxiety but not anxiety as cause
P22 Medication helped symptom of not eating
P22 Can't deny they calmed him down
P22 Focus on signs/symptoms of anxiety rather than reason behind anxiety

Relating to explanations

P3 Dreadful reaction to colonoscopy
P3 Didn't expect further complications from colonoscopy
P3 Complications after colonoscopy
P3 Attributes symptoms to complication of colonoscopy
P7 Given explanation for cause of pain
P7 GP assured him no damage from colonoscopy
P7 Not convinced no damage
P7 Defending as his reaction belief something wrong during colonoscopy caused symptoms
P7 Doctor found something wanted to examine further
P7 Lack of definitive answer means there was something there
P7 Concluding must not have been serious to act on
P7 Need for monitoring means must be something wrong
P10 Sense of urgency due to test being ordered every year
P11 Symptoms always discussed in relation to timing of colonoscopy
P11 Heart and head pounding after colonoscopy
P12 Attribution to colonoscopy only explanation
P12 Colonoscopy only test which showed something

P12 2nd/3rd colonoscopies didn't show up anything (ignoring this evidence to contrary)
P13 Before colonoscopy had no symptoms
P13 Ruling out inactivity/lifestyle as cause OR Health lifestyle not concordant with these symptoms
P16 Avoids question of what he thinks is causing it
P16 Don't know cause
P19 Assumption was tested for cancer
P19 Cancer ruled out by blood tests
P21 Only test showed something was colonoscopy
P21 Sense of urgency – justifying belief something wrong
P21 Not convinced is okay
P21 Validating possibility something wrong: passing blood
P21 Downplaying blood: might have been haemorrhoids
P24 Strangeness onset of symptoms after colonoscopy
P24 Connecting colonoscopy with symptoms
P27 Justifying attributing: pain of procedure
P27 Doctors don't corroborate his explanation

Disempowerment

Worthiness of care

P15 Not worthy of discussion with GP
P15 Wasting GPs time
P19 Since nothing visible, attention not warranted
P26 Symptoms don't warrant attention

Hopeless

P10 Helpless: "What can I do about it"
P19 No other tests left to do – what else is there to do?
P19 Helplessness
P21 Doesn't' know how to get answers – helpless
P25 Unexplainable
P26 Helpless: nowhere to turn

Negative emotional impact

P19 Lack of attention worrying
P25 No explanation frustrating to put it mildly

Search for empowerment in seeking information

P2 Request to see consultant to get answers
P7 Sought answer from GP whether damage done
P8 Anticipated regret if don't get tested then too late
P20 Need to catch cause before too late
P20 Search for explanation
P20 Desire to know what's wrong

P20 Would travel and spend to get answer
P24 Desire for explanation
P27 Desire to feel better
P27 Search if others have similar experience
P28 Need to know cause

Lack of control vs control

P23 In control of meds now – could come off them

Power differential

P7 Sign waiver to give power to doctor during procedure
P7 Power of doctors to make decision without consulting you
P7 Undermining opinion since not a doctor
P8 Not deserving of authority on diagnosing wife
P10 Lack of power to demand test
P10 Doctor power to decide if tests ordered
P26 No authority to demand tests
P26 Lack of power
P26 No choice but to trust doctors judgement

Empowerment

P12 Inability of doctor to know what you're experiencing (expert on own body)
P12 Body doesn't lie

Medical Validation

Power over legitimisation of complaint

P15 GP didn't think anything wrong
P15 Doesn't share opinion of GP

Desire for answer overrides desire to be well

P15 Conflict: Good to know tests normal but desire to know why
P20 Answer worth a lot of money

Need/lack of need for medical validation

P12 Doesn't mean something wrong
P12 Something has to be wrong (contradiction)
P12 Positive test gives answer
P25 Symptoms only visible with positive results
P28 Desire for tests for answers

Medical process fear-inducing

P8 Testing necessary evil
P13 Prepared for stress test so not apprehensive
P21 Urgency of doctor after colonoscopy frightening
P21 Thought something serious wrong

Fear/worry

Focus on heart

P12 Thinks heart is okay

Fear

P27 Scared/worried

Worry

P13 Uncertainty and worry
P20 Worry "Jesus Mary and Joseph"
P22 Symptoms worrying
P23 Worry will happen again and won't get enough sleep
P24 Not overly worried (implies some worry)

Inner struggles

Questioning (Is it mind (blame)? Is it normal? Confusion)

P7 Questions whether damage done during colonoscopy
P13 Worry over what's wrong
P13 Symptoms senseless
P13 Questioning why
P15 Questioning why
P16 Difficult to understand symptoms since no exertion
P23 Senseless: getting symptoms when relaxing
P24 Wonders whether did damage in colonoscopy
P25 "Should" be relaxed – questioning why
P25 Senseless
P27 Can't understand why
P27 Questioning why started after colonoscopy

Questioning adequacy of tests, medication & explanations

P9 Questioning why wife not referred earlier
P18 Always tablet to solve a problem
P22 Questioning how doctors can differ in opinions
P22 Meds highly addictive
P29 Wonders if some doctors listening

Accept and get on with it

P30 Accepting "it is what it is"

Techniques to accept: Belittling, Normalising, Ridicule, Dismiss, Console

P16 Berating self for complaining when others really suffering – not worthy
P24 Doesn't interfere with life
P29 Normalising bad reaction – luck

Dramatising

P12 Every day could be his last
P20 Emphasising significance of symptoms
P22 Something not right with system
P23 Body can't relax

Coping

P4 Difficulty/Struggle getting of Xanax
P4 Downplaying current dependence on medication
P4 Presenting self as not addicted to new meds
P17 Dependent on sleeping tablets to cope
P17 Defending need for sleeping tablets
P17 Regret starting sleeping tablets since addictive
P17 Demonstrating previous ability to sleep without problem
P23 Manage symptoms by walking
P23 Feels okay once active
P23 No coping strategy to help sleep

Inadequacy to address psychosocial

Dismissive

P7 Told not to worry about – worry dismissed
P15 GP dismissed symptoms
P16 Nobody wants to listen
P18 Symptoms dismissed by prescribing tablets
P21 Concerns were dismissed
P25 Only deal with what can see
P25 Dismissive of invisible symptoms
P26 Acceptance doctors can't do anything if can't detect anything
P26 Doctors dismiss symptoms as can't do anything
P30 Important to feel listened to
P30 Accepting of lack of tests if feel listened to
P30 Negative emotional impact when not listened to

Medical uncertainty

P4 Uncertainty: medicine trial and error
P5 Difference in opinion of doctors: uncertainty of medicine
P9 Knowledge and ability of doctors not enough
P9 Necessity of luck to survive
P9 Survival out of control of self and doctors
P9 Uncertainty of medicine
P20 Accepting medicine doesn't have all answers
P20 Body more complex than machine and harder to fix
P20 Lack of understanding of science
P20 Body complex machinery
P21 Money can't save you

P24 Accepting an answer is not easy
P27 They can't find reason

Inadequate information?

P5 Could find nothing wrong with heart
P11 GP happy nothing wrong with heart
P12 Tests showed up nothing
P15 GP told him all tests were okay
P15 No explanation
P21 Nothing showed up on tests
P21 Vagueness of explanation – it's okay
P28 Lack of explanation about procedures – need for more info

Adequacy of care?

P2 Disappointment when not getting to see consultant
P3 Uncertainty over lack of colonoscopy this year
P3 Attributing lack of test due to cut backs
P3 Prescribed medication for anxiety
P4 Medication helped appetite
P4 Addiction to Xanax not predicted
P4 GP encouraged discontinuation of Xanax
P4 Requested milder drug to ease off Xanax
P4 Sought advice from chemist to get off Xanax
P4 Every test under the sun – comprehensive
P6 Hospital made misdiagnosis of appendicitis
P6 In awe of advancement of medicine
P6 Hopeful no need for surgery in future
P9 Incompetence story: butchered wife's leg
P9 Wife referred too late for treatment
P9 Wife could have been saved if referred earlier
P10 Story of inadequacy: friend left on trolley
P10 Services unacceptable
P10 If can pay get more attention
P10 Feels lucky hasn't had long stay in hospital due to state of services
P11 Difference in opinions over adequacy of care
P11 Experiences shape perception of particular hospitals
P11 Chance whether have good experience in hospital
P14 Story of incompetence: friends operation cut across nerve causing pain for years
P14 Story of incompetence: mess of taking blood and no acceptance of responsibility
P15 Acceptance of incompetence in hospital – part and parcel
P18 Satisfied had comprehensive testing
P18 Paid for CAT scan for kidneys due to wait
P22 Story of incompetency: Doctor misdiagnosed wife with pollops
P22 Incompetency of doctors can cause death
P22 Difficulty in coming off meds

P24 Trusts GP with life – great confidence
P25 On treadmill – implies swift, abrupt care
P25 Detachment of doctors
P26 Inadequacy: need to go to America to get answers
P27 No apology from doctor
P27 Nurse sympathetic
P27 Abruptness of doctor
P29 Best treatment/specialist not enough
P29 Need for luck
P29 Easy for something to go wrong
P29 Signing waiver proof things go wrong
P29 Understanding can't always see consultant
P29 Some doctors instil more confidence than others
P29 Aloofness of some doctors
P30 Need for consideration of patients views
P30 Demeanour important
P30 Never badly treated
P30 Wrong and right way to treat patients
P31 Patients suffering due to cut backs

Deciding to seek help

Futility

P30 Futility in consultation

Defending decision to seek help

P2 Doctors advised tests
P4 Justifying worry over cancer: Friend's cancer wasn't detected
P11 Hospital clinic referred him to cardiologist
P11 Tests ordered to investigate heart
P19 Natural to seek help from doctor if something not functioning: analogy of mechanic for car
P24 Desire for solution to problem
P31 Attention only if calls ambulance

Influence of others

P3 Worry from others was losing weight
P3 Attention from neighbours and staff for losing weight
P4 Friend's cancer influencing worry over cancer
P4 Setting up son as credible source to reassure him about heart
P5 Son assured him he performed well on stress test
P8 Father died of cancer
P8 Wife died of cancer
P12 Son reassured him nothing wrong
P13 Son explained and prepared him for stress test
P29 Cousin died this year of cancer

Impact on life

P23 Heart pounding disrupts sleep
P23 Even sleeping tablet doesn't help sleep when heart pounding

Extra

P12 Symptoms don't occur in morning
P12 Symptoms occur when trying to relax
P18 Health more important than wealth
P18 Money means nothing without health
P25 Symptoms worst at night when relaxing

5. Laura's Interview

Relating to and negating real and presumed judgements

Real and presumed judgement

P16 Judgement of others
P33 Fear of judgement
P6 Assumption of stress
P6 Stress only alternative offered
P12 Stress assumed
P16 Depression supposed
P2 Pre-empts attribution to stress
P19 Judgement of others
P17 Presumes others attribute to mind
P23 Knows not to blame (blame ascribed to self when in mind)
P24 Confident in others' belief that not stressed
P26 Heart immediate assumption
P26 Assumption of heart by self and hospital
P32 Judgement it's in head
P22 Presumes judgement of in her head
P24 Fear of judgement in survey
P31 Judgement of GP
P40 Reluctance over survey
P41 Fear(?) of judgement of survey

Accepting vs negating psychological attributions

P2 Defensiveness about depression/stress
P2 Negates attribution to depression
P2 Annoyance at suggestion it's "mental"
P2 Judgement annoying
P3 Negating attribution to stress
P3 Context negates stress attribution
P3 Conflict: stress explanation doesn't fit
P2 Wake from sleep legitimises physical nature
P6 Knows not stressed
P6 Annoyance at assumption of stress
P6 Unfairly attributed to stress
P7 Not bothered with survey
P9 Context: relaxed – negating attribution to stress
P10 Negating assumption of stress
P14 Conflict with presumption
P16 Defensiveness of suggestion of depression
P22 Stress not legitimate explanation
P23 Negates stress explanation through personality description
P23 Wake from sleep justifies non-mental cause
P23 Exploring possible explanations through comparison
P24 Acknowledges legitimacy of depression as cause

P24 Acknowledges need for depression to be ruled out – not opposed
P24 Defends disbelief in stress explanation e.g. not worried, happy
P24 Defensive of suggestion of depression
P24 Eventual self assurance that performance in survey would conform with own perception
P39 Acknowledges has stressors
P39 Normalises level of stress
P39 Insufficiency of stress explanation
P39 Calm reaction to stress evidence to contrary of stress explanation
P40 Stress ubiquitous – normalising
P41 Indecision: struggle over survey (epitomises internal struggle generally? Didn't just throw in bin. Conflicted and undecided).
P41 Conceded to post survey

Relating to explanations

P31 Sought confirmation of hormonal possibility & suggestion dismissed
P34 Heart only cause has knowledge of
P35 Attempting to fit explanation of stress
P18 Attributed symptoms to low B12
P18 Convinced was B12
P18 Shocked when B12 normal
P21 Always attributed to B12
P34 Attempts to attribute to other physical causes
P43 Chest pain attributed to muscular pain
P23 Defends self and protects identity
P23 Compares herself to others to confirm identity
P16 Uncertainty over normality
P20 Appears common complaint
P34 Questions normality
P21 Struggle to dismiss media examples
P35 Attributes importance to context of occurrence
P35 Relaxed state doesn't fit with association of palps with exercise/stress
P16 Perceived inadequacy of hormonal explanation (laughter)
P13 Conflict: Fit vs palps
P13 Doesn't conform with perception of self as healthier

Disempowerment

Reality denied

P2 Reality denied
P11 Not believed
P14 Not believed
P14 Not believed
P14 It's in mind
P20 Professionals induce feeling its in head
P30 Lack of belief

P32 Not believed
P32 Not believed
P41 Feel its in head

Worthiness of care

P2 Medical care not warranted
P7 Help not warranted
P7 Unworthy of hospital "chucked out"
P14 Help not warranted
P16 Back turned
P26 Importance of heart warrants assumption of heart
P26 Wasting time
P29 Help seeking not valid
P32 Wasting time
P32 Time waster
P32 Not legitimate to discuss with GP
P41 Wasting time
P43 Lack of significance

Silence

P5 Keeps it hidden
P5 Conceals it
P5 Avoids discussion
P14 Easier to keep silent (can't win?)
P17 Concealing
P20 Reluctance to discuss
P20 Doesn't update on symptoms
P27 Silence
P34 Keeps silent
P19 Disapproving of woman who constantly talks about palps
P19 Dramatising comical
P34 Not worthy of discussion
P19 Concealment despite greater impairment
P43 Not worthy of complaint
P16 Silence to avoid labelling of stress
P17 Avoiding perception of psychological problem
P19 Avoiding perceived judgement
P27 Manage through silence
P15 Inadequacy of truth
P15 Feel onus to explain

Hopeless

P6 Hopelessness
P29 Hopeless
P29 No solution
P14 Nowhere to go
P29 Helplessness

P33 Helpless
P42 Helplessness
P7 Limbo & isolation
P15 Isolation
P16 Isolation (walking away emotive)
P31 Answer unattainable
P20 Abandoned
P12 Despondency

Negative emotional impact

P6 Dissatisfied
P7 Annoyance
P11 Frustration
P11 Disappointment
P11 Annoyance
P12 Disappointment
P14 Frustration of repetitiveness
P16 Feels let down
P20 Completely disheartened
P30 Frustration
P31 Frustration and uncertainty
P31 Frustration
P32 Frustration and annoyance
P32 Disheartening
P41 Emotional impact of doctor-patient communication
P42 Bad experience of hospital
P16 Embarrassment over lack of explanation
P19 Embarrassment
P20 Shame?
P26 Embarrassment and shame
P27 Embarrassment due to lack of answer
P32 Feeling foolish
P32 Embarrassment
P32 Embarrassment
P32 Power of doctor over emotion
P26 Feeling insignificant
P30 Insignificant

Search for empowerment in seeking information

P2 Desire for explanation
P7 Desire for explanation
P11 Desire to know why
P25 Desire for explanation
P25 Desire for understanding of tests
P25 Need for answers and support
P26 Need to know why
P26 Needs explanation

P27 Follow up needed
P28 Reassurance needed
P29 Added bonus of receiving info "nice"
P34 Clueless about possible causes
P40 Only desire is information
P41 Desire for reassurance
P12 Need for alternative explanation
P15 Need for explanation
P16 Need for info
P3 Search for alternative understanding
P3 Search for answers
P21 Constant search for explanation
P33 Question why
P33 Desperation
P15 Imagined helpfulness of information
P25 Inability to judge own performance in tests
P25 Info on test results would reassure
P26 Information soothes worry
P15 Sharing similar experience with work colleague
P34 Never investigated herself
P21 Media examples offer explanations
P25 Need for closure

Lack of control

P1 Frequent
P2 Uncontrollable
P2 Unpredictable
P3 Constant symptom
P3 Uncontrollable
P2 Uncomfortable
P8 Unpredictably returned
P33 Out of control
P36 Uncontrollable

Power differential

P14 Medical opinion more powerful and valid
P22 Uncomfortable making suggestions: power differential
P22 Feeling foolish suggesting possibilities
P23 Inability and discomfort to suggest
P33 Inferior position to GP
P34 Desire to ask questions
P33 Inability to discuss with GP
P38 Tests sound intimidating
P22 Power belongs to medics

Empowerment

P28 Relief that believed

Medical Validation

Power over legitimisation of complaint/ Validation

P2 Hospital procedures legitimised complaint
P8 High pulse and doctors reaction legitimised it
P10 Legitimised complaint
P10 Heart-beat rate medicalised
P26 No legitimate illness
P27 Not medical without abnormal test
P27 Illegitimacy of claiming medical condition
P28 Abnormal test validates symptoms
P29 Tests validate complaint as real
P8 Not in mind
P10 Felt validated and believed
P10 Not in head
P10 Validation
P14 Lack of validation
P20 Attention validates it
P20 Abrupt end to validation
P20 Relief of medicalisation
P14 Future tests instils hope
P27 Waiting for appointment gives feeling of progression
P29 Normal test results knock you down ladder
P29 Hope of tests quashed
P30 Constant knock backs
P30 Tests and apps progression

Desire for answer overrides desire to be well

P8 Happiness clear results
P18 Disappointment when explanation (B12) disproved
P18 Disappointment over normal test results
P19 Explanation more valuable than normal results
P19 Conflict: desire to be well vs desire for answer (desire for answer overrides)
P22 Expect and hope for abnormal test
P28 Satisfaction with abnormal test
P29 Conflict: hope nothing wrong vs please show something
P32 Frustration of normal results
P14 Hopeful tests not normal
P30 Hopeful tablets would work (i.e. hopeful heart condition)

Need for medical validation

P15 Embarrassment about lack of medical explanation
P19 Need for validation
P19 Contented with explanation and reason (Contradiction)
P22 Abnormal test validates symptoms
P29 No belief with normal tests
P7 Searching for medical attribution

P18 Search for alternative medical explanation
P18 Need for detectable abnormality
P15 Acceptance of non-seriousness possible with alternative explanation
P16 Easier to cope with reason
P26 Unresolved without information
P28 Easier to dismiss with reassurance

Enabling valid discussion

P5 Not legitimate to speak about it now
P17 Clear results disables further discussion
P19 Moaner without legitimate medical complaint
P19 Her complaining not warranted
P20 Keen not to be perceived as moaning
P27 Worthy of discussion when medicalised
P27 Medical explanation only discourse
P7 Medical explanation legitimises it – enables discussion

Urgent reaction fear-inducing

P8 Urgency shocking
P9 Medics' actions frightening
P10 Urgent reaction
P10 Urgency induced fear of something seriously wrong

Fear/worry about heart

Focus on heart

P1 Awareness heart abnormal
P1 Awareness heart abnormal
P1 Explanation: heart in throat
P2 Explanation: heart in throat
P9 Assume something wrong with heart
P9 Belief heart abnormal (names heart not chest)

Fear

P9 Frightening
P10 Fear of heart attack
P10 Instilled fear of heart attack
P11 Waiting anxiety inducing
P32 Panic with initial symptoms
P21 Uncertainty and fear

Worry

P27 No info worrying
P27 Distancing herself from appearance of worrying yet acknowledges worry
P33 Worry inevitable when bad – defending herself
P42 Worry about heart or other physical problem (Contradiction)

P42 Progression from abstract to self (Attempting to distance from worrying behaviour)
P43 Distance herself from attribution to worry
P8 Lack of worry
P41 Worrying inevitable without reassurance

Inner struggles

Questioning (Is it mind (blame)? Is it normal? Confusion)

P2 Question reality of it – is it in mind?
P2 Not to blame – physical not mind
P11 Question reality of sensation
P23 Questions whether self caused
P23 Questioning of self and identity
P23 Identity challenged
P23 Conflict: is it me vs I know its not
P33 Question yourself
P8 Uncertainty why
P11 Lack of understanding
P13 Senseless
P13 Confusion
P13 Senseless
P4 Questioning whether to put it to bed
P21 Persistence senseless
P21 Question possibilities
P21 Drama in mind
P21 Thoughts uncontrollable
P22 Not purposefully searching for explanations
P22 Doubt
P19 Questioning validity of her explanation

Questioning adequacy of tests, medication & explanations

P16 Questions validity of hormonal explanation
P18 Confusion over lack of fit of perceived explanation
P34 Puzzling that happens when relaxed
P35 Contexts puzzling
P35 Context of occurrence opposite to norm
P35 Feeling of uniqueness
P33 Thoughts of possibilities dangerous
P22 Possibility of undetected cause
P3 Confusion & reluctance over heart medication (not worthy?)
P4 Confusion: tablets helped a little but not eliminated
P4 Reluctance to rely on medication
P4 Indecisiveness: internal struggle
P12 Tablets pointless
P29 Contradiction of heart medication

P29 Confusion about meds
P3 Contradiction: Heart normal but prescribed heart medication
P3 Context of occurrences confusing
P6 Uncertainty over validity of stress test result
P6 Lack of understanding of how stress test worked
P11 Uncertainty of relevance
P25 Uncertainty over effectiveness of tests
P35 Questions whether treadmill test appropriate for her
P36 Acknowledges appropriateness of holter test
P8 Uncertainty over results

Accept and get on with it

P3 Acceptance
P7 Reluctantly accepted "ah"
P8 Acceptance
P27 Acceptance
P28 Feeling of proof enables acceptance
P30 Acceptance not life-threatening
P31 Acceptance
P36 Acceptance
P43 Acceptance
P2 Get on with it
P4 Just get on with it
P5 Let go: indicates some control?
P5 Get on with it
P7 Forget about it
P10 Gets on with it
P12 Get on with it
P12 Get on with it
P14 Get on with it
P32 Forget about it
P32 Get on with it
P36 Learn to let go
P27 Get on with it
P10 No other choice but to accept
P41 Need to accept
P17 No alternative but to get on with it
P28 Lack of interference
P29 Need to cope alone if not medical
P42 Potential to dominate life
P42 Doesn't allow impact
P6 Worry pointless

Techniques to accept: Belittling, Normalising, Ridicule, Dismiss, Console

P2 Downplays impact
P2 No reason to worry
P3 Downplaying

P5 Downplays its affect on life
P8 Lack of interference
P9 Downplays symptoms
P10 Doesn't interfere
P17 Belittles them
P23 Belittles it as just a feeling
P27 Doesn't bother me
P30 Belittles as feeling
P40 Lucky and grateful
P40 Belittles complaint
P31 Belittles them
P3 Normalises them
P14 Normalising
P30 Inevitable feeling
P30 Normalising: like butterflies (normal/common)
P30 Deal with by normalising
P32 Acceptance as normal
P36 Normalises as feeling
P36 Only explanation normal
P41 Normalising
P4 Feeling: butterflies in throat
P3 Blocks thoughts
P7 Quash uncertainty/hope
P8 Dismissed them herself when re-occurred
P13 Ignore confusion
P20 Dismisses it (mirroring treatment by hospital)
P27 Dismissive due to lack of validation
P30 Dismissive of it (self)
P33 Attempt to dismiss thoughts of other possibilities
P33 Stops them from invading thoughts
P34 Dismissed it (Self)
P34 Puts end to thoughts
P34 Denies thoughts
P42 Desire to dismiss
P20 Judgement of self to cop on
P21 Scolds her inner doubt
P22 Ridicules her uncertainty
P21 Consoling oneself that hospital was comprehensive – their judgement better
P22 Self soothes fears
P33 Self-soothes by diminishing their importance
P35 Diminishes their significance
P42 Conflict: severe vs just flutters (dependent on purpose of speech)
P43 Diminishes complaint

Coping

P2 Adapted to it
P2 Ability to cope

P3 Awareness constant
P4 Procedure for coping: breathing
P7 Learned to live with
P13 Walking to clear head
P17 Capable of managing
P28 Coping strategies needed
P28 Forced to cope by oneself
P28 Learn to expect as part of life
P30 Onus to cope by oneself
P33 Controls impact
P35 Awareness of them
P43 Happy with coping (contradiction to earlier)

Inadequacy to address psychosocial

Dismissive

P6 Dismissive
P6 Closed case
P7 Dismissed as healthy
P8 Dismissed
P10 Dismissed
P14 Belittled
P14 Goodbye – coldness
P15 Dismissive
P16 Dismissed as stress
P26 Dismissed
P30 Complaining prompted heart medication
P31 Tablets dismissive
P31 Tablets opposed to offering explanation

Uncertainty about psychosocial

P3 Trial and error of medication
P3 Trial and error of medication: uncertainty
P31 Meds trial and error

Inadequate information

P6 Answers inadequate
P11 Vagueness about result
P11 Vagueness about test result
P12 Reasonable to expect info
P27 Reasonable to expect info
P20 Expects answers from medics
P26 Assumption that medics know
P26 Neglect of medics to impart knowledge
P25 Helpfulness of nurse due to offering of explanations
P11 No news is good news

P2 Cause unanswered
P2 Unresolved
P8 Lack of answers
P19 No explanation
P30 No answer
P36 A million questions unanswered
P38 Left in the dark
P6 Lack of communication
P7 Lack of communication
P8 No follow up
P10 No follow-up
P11 Lack of feedback
P12 Lack of discussion
P14 No follow up
P32 No answers
P11 Expectations unknown

Insufficient care

P6 Expected more from consultation
P6 Insufficient
P6 Not comprehensive enough
P7 No assistance offered
P11 Follow-up desired
P12 Lack of support
P13 Consultation not thorough
P13 Not explorative of possibilities
P14 Lack of interest
P16 Need for support
P16 Follow up would have changed her
P17 No support
P20 Inadequate support
P23 Other possibilities not considered by doctor
P25 Unhelpulness of lack of follow up
P26 Lack of will to help
P26 Neglect
P27 Nature of complaint warrants follow up
P28 No support
P31 Sought advice and reassurance but none
P32 Support withdrawn abruptly

Deciding to seek help

Futility

P4 Struggle with point of seeking help
P6 Presuming inaction
P6 Futility in discussing

P7 Pointlessness
P8 Futility
P9 Futility
P9 Turned off returning to hospital
P12 Futility
P14 Future help seeking futile
P14 Futility
P14 Pointless
P17 Futility in discussing
P20 Expectant of repetitive hospital experiences
P22 Avoids doctor
P20 Futility of hep seeking
P26 Futility
P29 Questions possibility of progression
P29 No progression
P30 Futility of tablets
P30 Pointless
P31 Further tests futile
P31 Wasting "my" time (not just doctors)
P31 Inconvenience and futility
P32 Pointless
P42 Hopeful no need for further hospital care

Hope of alternative medicine

P12 Experimented with acupuncture
P12 Perceived benefit of acupuncture – improved sleep
P12 Happy to continue with acupuncture (no conflict like with meds)

Defending decision to seek help

P8 Sought help for initial symptom
P9 Defending help seeking behaviour "worst experience"
P9 Seeking help when "bad"
P20 Struggles with decision to seek help when bad
P31 Lack of desire for further action
P42 Severity renders help-seeking unavoidable

Pressure from others

P5 Worries husband
P5 Avoids worrying husband
P5 Discussion prompts pressure to investigate
P5 Physical reaction – visibly noticeable
P5 Avoidant of pressure to seek help
P17 Hides from mother to prevent worry
P17 Protect family from worry
P17 Avoid family pressure for answer
P19 Others shock at lack of explanation
P21 Pressure of others to seek further help

Impact on life

P35 Disrupts sleep

Extra

P5 Context: sickness/run down

P5 Difficulty in verbalising

P13 Context: enjoyable activity of walking

6. Mark's Interview

Relating to and negating real and presumed judgements

Real and presumed judgement

P10 Explanation of muscular pain
P13 Once other causes ruled out it's put down to muscles
P24 Perceives blood tests to be ruling out cancer

Accepting vs negating psychological attributions

P11 Wife sought confirmation whether it was in head
P18 Metaphor to get off chest: emotional relief
P19 Felt relief in body when asserted at work (mind body link)

Relating to offered explanations

P3 Pain precipitated by pushing heavy bins at work
P4 Acceptance needs to do heavy lifting at work
P11 Heavy work to blame for pulled muscles
P11 Attributes to over-work
P11 Illegitimate work to blame
P12 Deduces must be overwork
P12 Accepting of muscle explanation
P12 Relating to muscle explanation – physical strain at work
P12 Blaming lack of help at work
P12 Wrongful working conditions to blame
P13 Relating to muscle explanation
P18 Attributes to over-work
P18 Illegitimate work the cause

Disempowerment

Reality denied

P11 Defending reality of them "hit you like a tonne of bricks"

Worthiness of care

P7 Feels unworthy of ambulance
P7 Fear will take ambulance from worthier patient

Silence

P3 Doesn't reveal pain to anyone
P3 Physically evident when in severe pain – unable to conceal physically
P5 Conceals pain
P17 Visible to wife when in pain
P17 Conceals pain from others

Removing validation

P7 Embarrassment when not heart attack

P7 Difficulty in getting needle in due to aspirin (using story to change focus from embarrassment)

Search for empowerment in seeking information

P10 Seeks advice from GP
P11 Demanded explanation on 3rd visit
P11 Demanded answer

Lack of control vs control

P16 Pride that hill-walking now
P22 Luck – unpredictable and uncontrollable
P24 Pride has reduced cholesterol through losing weight
P25 Feels better since eating healthier – some control
P25 Accepting of need to eat healthier
P25 Confident in ability to lose weight

Limbo

P14 Nervous waiting for results
P14 Questioning while waiting

Power differential

P8 Embarrassed when can't understand questions
P13 Undermines his knowledge "disorder probably wrong word"
P14 Power differential – nosy to be asking
P18 Need to do what told

Empowerment

P12 Relief of explanation
P12 Empowered with explanation
P14 Huge relief to get normal results
P14 Knowledge of normal results eases mind

Fear/worry about symptoms

Focus on heart

P3 Expectant of heart attack

Fear

P5 Imagines worst case scenario
P5 Worries going to die or something bad will happen

Worry

P13 Expectant of finding cancer
P13 Normalising expectation of cancer
P14 Inevitability of thinking about cancer
P14 Associates hospital with cancer

P14 Worry history repeating and will die of cancer

Inner struggles

Questioning (Is it mind (blame)? Is it normal? Confusion)

P5 Mind blank vs mind racing
P11 Questioned whether in head
P12 Questioning cause
P12 Rules out possible causes
P13 Lots go through mind
P14 Questions whether has cancer
P14 Doubt about getting good results – "if"
P14 Defending thoughts – everyone's different
P22 Uncertainty about future of symptoms
P22 Issue not resolved/mind not at ease

Questioning adequacy of tests, medication & explanations

P14 Uncertainty about meaning of tests

Accept and get on with it

P4 Works through it
P4 Has to cope throughout work
P4 Acceptance will last hours
P5 Accepting – "it's grand"
P13 Copes "get through it"
P14 Accepting of normal results
P19 Acceptance "what I go through"
P21 Gets through it

Techniques to accept: Belittling, Normalising, Ridicule, Dismiss, Console

P5 Downplaying symptoms in last month
P5 Dismisses symptoms to boss
P6 Not much impact on life – downplaying
P14 Downplays worry
P19 Downplays "feeling Grand"
P19 Critiques own negative thinking
P23 Doesn't affect life
P23 Tells himself to think positively
P23 Consoles self will ease
P24 Downplaying: "it does be grand"

Dramatising

P3 Dramatises severity of pain
P3 Unable to compare to heart attack since hasn't had one
P4 Severe pain lasts 8/9 hours
P4 Discomfort of pain
P5 Physically visible when in pain

P8 Huge physical impact: curls in ball and unable to move or breathe
P8 Tightness in chest unbelievable
P11 Dramatising pain "wouldn't wish on worst enemy"
P13 Difficulty breathing with pain
P15 Doubled up in ball with pain

Coping

P4 Copes by distracting thoughts
P4 Tries to work through pain
P5 Desire to lie down doing nothing when severe
P5 Hard to work through pain
P6 Conflict: pain vs need to work
P6 Dependent on him at work
P6 Increased pressure if leaves work
P7 Manages by lying down and trying to get comfortable
P7 Takes paracetemol to manage pain
P8 Manages by sitting for a few minutes when gets twinge
P8 Dismissive of boss – need to deal with on own
P15 Conversing with others in hospital helps you forget about it
P16 Leave me be
P16 Need to be on own to deal with pain
P16 Avoidant of others when in pain
P17 Leave me be: wife
P17 Leave me be
P17 Copes by sitting on floor for hours
P17 Relief to be on own when in pain – more comfortable
P17 Conflict with wife over method of coping: sitting on floor
P17 Waiting to see if medication eases pain
P17 Takes paracetemol to manage pain
P17 Desire to cope on own
P18 Relief in chest when asserted self at work
P19 Discussing symptoms with family coping mechanism
P19 Relief in discussing symptoms
P19 Normalising desire for family in hospital
P19 Thinking positively coping strategy (offers as advice)
P20 Diagnosis of lymphedema stroke cellulitis – lots of symptoms & hospital treatment
P21 Worries how will cope with chest pain & lymphedema symptoms
P23 Manages with paracetemol
P23 Destroyed stomach with difene
P23 Over-use of difene for pain management
P23 Takes paracetemol for slight pain
P23 Paracetemol can ease pain
P24 Tries to work through it

Inadequacy to address psychosocial

Dismissive

P12 Doctor waits to see what happens – not dismissed

Medical uncertainty

P24 Uncertainty of doctor

Inadequate information?

P7 Everything "seemed" okay – vagueness
P10 GP discusses it with him
P11 Spasms in muscles around heart – explanation
P11 Lack of explanation initially
P11 No explanation – found nothing wrong
P11 Lack of explanation inadequate
P13 Test results "more or less" conveyed to him
P19 Doctors' information helpful
P24 Doctor advised to lose weight

Adequacy of care?

P8 Accepting of wait and delays in hospital
P9 Acknowledges medics have tough job
P9 Worthiness of own opinion on services due to frequent use
P9 Admiration for doctors working under pressure
P9 Commending staffs performance
P9 Acceptance of delay
P9 Admiration for staff
P9 Lack of frustration with delay
P9 Respect for staff
P9 Accepting not priority in A&E
P10 Accepting of services
P20 Appreciative staff have tough job
P20 Doesn't allow hospital experience to upset him: "take in your stride"
P20 Personality not suited to group support

Deciding to seek help

Defending decision to seek help

P3 Justifying hospital visits due to severity
P4 When unbearable calls ambulance
P4 Justifying need for ambulance – "left for dead"
P5 Accustomed to hospital
P5 Tells self go to hospital
P5 When severe only thought is hospital
P7 Goes to hospital if pain worsens
P7 Reluctance to go to hospital

P7 Defending need for ambulance: severity of symptoms
P10 GP sends him to hospital
P10 Only visits GP for prescriptions now
P12 Leaves work if not able
P12 Hospital legitimate way of leaving work – boss worries
P13 Frequently attending hospital
P14 Seeks reassurance doesn't have cancer
P15 Sought ambulance first time happened
P18 Seeking advice
P20 Seeks advice and info from GP
P23 Majority of time works through pain
P24 If unbearable seeks help
P24 Attempts to get last minute apps with GP before hospital
P24 GP either gives meds or sends to hospital
P24 Sent to hospital to put mind of doctor at ease

Influence of others

P5 Boss questioning of pain
P5 Conflict with boss when in pain
P6 Pressure to remain at work
P6 Concern for losing job
P6 Pressure to keep everyone happy
P6 Reluctance to reveal to boss
P6 Boss stressed if he leaves
P6 Boss panics (About him or work??)
P6 Belittles panic of boss
P7 Family reassure him of his need for ambulance
P8 Boss questioning
P8 Downplays to boss
P8 Reassures boss not to worry
P12 Boss gives out for not working
P12 Defends himself to boss for not working
P12 Assertiveness to boss that can't work
P12 Boss becoming more understanding
P12 Assertive with boss: "good luck"
P12 Conflict with boss over leaving work
P13 Accepting of conflict with boss
P14 Mother's cancer plays on mind
P14 Dad thinks its cancer
P14 Uncle's death from cancer plays on mind
P15 Mother panics
P15 Annoyance over mothers concern
P15 Attempts to dismiss mothers panic
P15 Annoyance with mothers concern and instruction
P16 Neighbours concerned and panicked
P16 Mother interfering
P16 Panic of friend when in pain

P16 Friend rang ambulance due to fright
P16 Friend taking very seriously – wouldn't let him drink water
P17 Pre-empts wife insistence of going to hospital
P17 Wife's concern exacerbates it
P17 Wife panics
P17 Wife tries to force him to hospital
P17 Dismisses wife's concern
P17 Aggravated by wife's panic
P17 Threatens wife he will leave
P17 Additional stress of family's worry
P23 Boss questioning of using medication
P23 Dismisses boss's concerns
P24 Others pressurise to go to hospital

Fear/worry

P18 Worry over remaining in hospital
P18 Consoles self hospital stay out of his control

Impact on life - work

P4 Job stressful
P6 Worries about not being able to pay mortgage
P6 Normalising worry associated with losing job
P6 Life all about job and money
P6 Accepting of dependence on him to remain at work
P6 Pride to have stayed at work so long
P6 Routine life
P6 Pressure to do work at home also
P7 Unable to imagine different life without pain
P7 Unable to work or do work in house
P9 Breaks accepted by boss if machine cover
P18 Asserted self at work to improve work-load
P18 Defensive at work: hands off
P19 Stress remains at work – more to get off chest
P19 Wait & see if changes at work will impact on life
P21 Stressful coping with illness at work
P21 Pride in self for staying at work
P22 Burden of getting to work
P22 Frustration and anger with boss
P22 Need for money overrides desire to quit
P22 Doesn't stand up for self "soft"
P22 Hopeful work situation will improve
P22 Wait & see: cross bridge when comes to it
P22 Nonchalant about work: will drop them (contradiction)
P22 Pre-empting annoyance of boss
P22 Expecting to be fired
P22 Worry will be fired

P23 Worry will be fired
P23 Consoles self will deal with firing if arises
P23 Anger at expectant dismissal
P23 Berates himself for getting down about work
P24 If unbearable then gives up work
P24 Defensiveness – pre-empting annoyance of boss